*Understanding the Experience of Treatment for Anorexia*

*Nervosa:*

*The Perspective of Patients who Drop Out of Services*

By

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# ABSTRACT

## Understanding the experience of treatment for anorexia nervosa: the perspective of patients who drop out of treatment

### By Alison Payne

'Drop-out' is a problem common to many mental health services. Within services for anorexia nervosa the issue is even more problematic given that the disorder has a potentially fatal outcome. Research suggests that approximately 50% of patients drop-out prematurely from treatment services for anorexia nervosa and there has been a concerted effort over recent years to try and understand and overcome this concerning phenomenon.

This research set out to investigate the possible reasons for drop-out from services for women diagnosed with anorexia nervosa. An additional aim was to investigate the personal significance of anorexia nervosa and the impact that treatment has on changing this.

This research investigated the reported experiences of 8 women who had previously attended a local specialist eating disorders service. The participants were asked to provide a narrative account of their experiences of treatment which was then followed up in an interview. One participant was only able to provide a narrative account and 3 participants preferred to be interviewed without providing a written narrative.

The information obtained from the narratives and interviews was analysed using a social constructionist revision of grounded theory.

A central theme of control emerged which was affected by interactions with the wider social system. The accumulative battle for control between the anorectic and others (such as family, friends and professionals) appeared to result in the act of dropping out as the treatment approach, timing and context recreated the setting conditions of lost control.

The organisational and clinical implications of this model are discussed in the light of existing conceptualisations of drop-out and anorexia nervosa.

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## INTRODUCTION

### 1.0 An overview of the introduction

'Drop-out' is a metaphor commonly used in the psychological literature to describe a person who prematurely withdraws from treatment services. Interest in the topic of drop-out from services for anorexia nervosa arose from my concern about the high rate of drop-out from eating disorder services and accordingly the current provision of appropriate treatments. Recent research in a local specialised eating disorders service discovered approximately half of all patients in their service dropped out of contact (Button *et al*, 1997). It appears that even the most severely affected patients are often unmotivated for therapy (Engel and Wilms, 1986). Clearly, this issue is of particular concern given that anorexia nervosa has a potentially fatal outcome (Theander, 1985).

In this section, it is my intention to provide an outline of the historical developments in relation to the definition and treatment of eating disorders. Epidemiological and aetiological debates will not be addressed in detail here, as they have been well documented elsewhere (for example Garfinkel and Garner, 1982) and are not considered central to the aims of this research.

Drop-out is a phenomenon common to many other areas of applied psychological practice, and therefore I shall be drawing on developments from other areas, and contrasting these

with available theories and literature regarding the focus of this study, drop-out from services for anorexia nervosa.

I shall then attempt to analyze critically the main areas of debate and contention, given the available research. Initial conclusions will be drawn and questions and areas of interest for this study will be highlighted. I will argue that because of the diversity of experiences and meanings in the current debate, there is a need for an alternative framework for understanding the issue of drop-out.

## 1.1 Definitions and Theories of Aetiology

Defining anorexia nervosa remains a contentious issue. Texts outlining the history of the disorder reveal the influence of culture, society and politics on its ever changing definition (Mott and Lumsden, 1994). As Robertson (1992) states, 'Anorexia nervosa has become a complex combination of folk term and medical category' (p.19). Furthermore, she suggests that the term has pervaded everyday speech and become part of a way of categorising self starvation as an illness.

The early clinical descriptions of Gull (1874) and Lasègue (1873) attributed anorexia nervosa to a nervous origin. Lasègue (1873) in his paper 'On hysterical anorexia' argued that the cause of anorexia lay in women's emotional and unstable nature. Therefore the disorder was viewed as a predominantly 'feminine' condition (Hepworth and Griffin, 1995).

There was a move away from the 'nervous origin' of the disorder in the early 20th century as it was linked with pituitary insufficiency (Simmonds (1814, 1816, as cited in Blinder and Chao, 1994). In addition, the First World War challenged the notion of hysteria as primarily a feminine disorder as the medical profession was faced with the vast numbers of men suffering hysteria in the form of shell shock. Non-eating also became evident in such men and no single organic explanation could be found for hysteria and non-eating (Roberston, 1992).

The disorder was rediscovered as a clinical entity in 1949, when it was found that only a quarter of Simmonds' patients lost extreme amounts of weight. There has since been a gradual shift towards a psychological understanding of the disorder, although this has tended to follow a cyclical rather than linear pattern. This may in part be due to the enduring debates regarding the relationship between body and mind.

In terms of clinical developments, there have been significant theoretical contributions, including psychoanalytic in the late nineteenth century (Freud and Janet, 1985-1905, as cited in Brumberg, 1988), psychosocial in the 1960's (Bruch, 1962), systemic in the 1970's (Minuchin et al, 1978), biopsychosocial in the 1980's (Lucas, 1981) and neurobiologic in the last decade (Hagman, 1992).

There seems to be some consensus that anorexia nervosa is determined multifactorially by a combination of biological, social and psychological factors. Garner and Garfinkel have been two prominent researchers in the academic arena of eating disorders, whose work

heralded a shift away from linear theories of causation towards an analysis of the multiple factors involved in this complex disorder. Their extensive research in the 1980's made an enormous contribution to understanding the predisposing, precipitating and perpetuating factors of the disorder. For example, in terms of predisposing factors, Garner and Garfinkel (1980) documented a trend of increasing pressure on women towards excessive thinness, such as a 70% increase in diet articles in popular women's magazines in the 1970's. Such research led to an increased awareness of the socio-cultural factors in anorexia nervosa.

As anorexia nervosa seems to be predominantly confined to women in Western societies, feminist researchers have raised questions regarding the role of women in male patriarchal societies and the impact this has on the development of eating disorders. Orbach (1978) has argued that anorexia nervosa is a stance of rebellion, so that by taking control of her body, the woman is not participating in society's objectification of her.

Although there are varying theories regarding the way in which culture and anorexia nervosa operate, numerous studies have supported feminist theories regarding the pressure in industrial societies to conform to a slim ideal (for example Garner and Garfinkel, 1980). As Dolan and Gitzinger (1994) suggest '..disordered eating and attitudes are so common that, as a woman, you are abnormal if you do not follow diets and worry about your weight' (p. 1).

However doubts have been cast on this theory by a recent study of the Caribbean island of Curacao where obesity is socially accepted (Hoek *et al*, 1998). The researchers expected to find very few cases of anorexia nervosa when they reviewed the medical notes of all inpatients of the General Hospital between 1987 and 1989. They were surprised to find that six cases of anorexia nervosa were identified and the yearly incidence of anorexia nervosa was 2.6 per 100,000 women, which is in the range of rates reported in Western societies.

Studies of families and twins indicate that biological or genetic factors may predispose individuals to the disorder (Strober *et al*, 1990) and help us to understand why only a few women go on to develop full-blown anorexia nervosa. For example Holland *et al* (1984) studied 42 female twin pairs in which at least one twin had anorexia nervosa. They discovered that there was a 56% concordance for anorexia nervosa amongst monozygotic twins and 7% for dizygotic twins. However, separating cause from effect remains problematic as the shared environment (such as the family) may also contribute to the onset.

Dynamics within the family have been postulated as contributory factors, although there is some dispute between various schools of thought with regard to the exact way in which interactions contribute to the onset of the disorder. Minuchin *et al* (1978) characterised dysfunctional families as enmeshed, over-protecting, rigid and lacking in conflict resolution. However Kog and Vandereycken (1985) found that the notion of the typical anorexia nervosa family could not be supported empirically.

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The psychological literature has also focused on various personality characteristics which may play an important role in both the development and maintenance of anorexia nervosa. Bruch (1973) has outlined three areas of psychological dysfunction in the disorder. These are (a) a distorted body image, (b) inaccurate perception of internal states, and (c) a paralyzing sense of ineffectiveness. Perceived control, low self-esteem, self-directed hostility are also factors which characterise the anorectic patient (Williams *et al*, 1993). Garfinkel and Garner (1982) summarized the results of a number of studies and found that a threat of loss of self-control and/or loss of self-worth were common precipitants in the studies they reviewed.

Literally, anorexia means lack of appetite or avoidance and loathing of food (Blinder and Chao, 1994). However, in clinical use, this definition is considered inappropriate as appetite is rarely diminished until the latter stages of the disorder (Button, 1993). The current convention in clinical practice is to define anorexia nervosa according to the criteria of the Diagnostic and Statistical Manual, of which DSM IV is the most recent version (American Psychiatric Association, 1994) (see appendix 1).

Anorexia nervosa affects women more than men in a ratio of approximately 10:1 (Andersen, 1993). It has been argued that diagnostic systems such as the DSM IV draw on the early discourses of Gull and Lasèque and this reproduces the notion that anorexia is an inherently feminine disorder affecting mostly young women (Hepworth and Griffin, 1995). Andersen (1993) has implied that the current diagnostic criteria are gender biased, as a duration of three months amenorrhoea is required in the diagnosis of anorexia nervosa in

females. However, there are no analogous criteria for males despite abnormal reproductive

hormone functioning being well documented in male sufferers.

According to Robertson (1992), who argues from a feminist perspective, diagnostic

procedures convert the experience of anorexia nervosa to male meanings which 'remove

her from any sense of herself that differs from the meanings enshrined in male ideology'

(p. 69).

Despite the clear focus in the literature on women's experience of anorexia nervosa,

research suggests that there are few clinical differences between male and female sufferers

(Margo, 1987). Furthermore, it appears that in contexts where weight and size are

significant (e.g. for jockeys) men are more likely to develop eating disorders (King and

Mezey, 1987). In a study of anorexic and bulimic patients, Herzog *et al* (1984) found that

26% of the male patients were homosexual, versus 4% of the females. They suggest that

the 'gay' male culture places greater emphasis on aesthetic appearance and this in turn may

place them at greater risk for eating disorders than heterosexual men. This suggests that in

contexts where there is an emphasis on physical appearance, men are also susceptible to

societal pressures to conform to a slim ideal. Research like this has therefore challenged

the notion of anorexia nervosa as an entirely 'feminine' disorder.

Given the lack of clarity and consensus regarding the definition of anorexia nervosa, it may

be argued that it is a socially constructed phenomenon. Robertson (1992) has suggested

the term 'anorexia nervosa' is merely a clinical label ascribed to make irrational

consumption understandable. The French philosopher Michel Foucault has described how certain aspects of social behaviour, such as eating and non-eating, become transformed into areas of life subject to the authority of others. He describes this as a process of subjectification, where understandings of individuals are mediated by an external authority (Foucault, 1971, as cited in Robertson, 1992).

A recent study by Benveniste *et al* (1999) investigated lay theories of anorexia nervosa with the aim of identifying discourses which characterize and conceptualise the term anorexia nervosa. Findings suggested that lay theories appeal to the notion of anorexia nervosa as a psychopathology and therefore impetus for change is focused at the level of the sufferer. They conclude that such lay theories reproduce and maintain existing concepts and practices.

This section has briefly addressed some theories of aetiology alongside a discussion of the ways in which anorexia nervosa has been conceptualised and defined. Although there have been considerable contributions to understanding the disorder, these have all clearly been influenced by social, cultural and political developments. Therefore explanations have tended to emerge in cyclical themes relative to such wider influences. Unfortunately, such phases of theoretical dominance have resulted in a neglect of the meaning of starvation and the impact of context on its meaning.

Clinical explanations tend to be focused on the individual patient to the neglect of the wider societal context. Whilst socio-cultural notions are useful in conceptualising

predisposing factors they do not adequately explain why only some women develop eating

disorders, when all women are exposed to societal ideals regarding weight. In searching

for answers regarding the causes of anorexia nervosa, we may be neglecting equally

important questions regarding the individual meaning of anorexia nervosa in particular

contexts.

In the following section, these themes will be discussed in terms of the way in which they

have impacted upon the treatment of anorexia nervosa.

## 1.2 The treatment of anorexia nervosa

Despite the extensive number of research papers published on anorexia nervosa over recent

years, there remains a lack of consensus regarding both explanations of anorexia nervosa

and effective treatment programmes (Agras and Kraemer, 1983; Herzog *et al*, 1992;

Benveniste 1999).

The treatment of anorexia nervosa (like its definition) has coincided with more widespread

social changes, frequently related to developments in scientific medicine (Merchant, 1980).

For example, as Gull (1874) moved away from attempting to determine an organic cause

for anorexia nervosa, his methods of treatment turned away from medical science, to the

rapidly developing discipline of psychiatry (Hepworth and Griffin, 1995).

The treatment advocated by Gull (1873) was 'moral control' to bring back the 'patient's mental equilibrium' (p. 534-5). It was believed by controlling the patient's behaviour and environment, the individual would develop self-restraint (MacSween, 1993). The individuals' relations and friends were not considered to be conducive to establishing mental equilibrium and therefore treatment was confined to the context of the asylum.

A study which had profound implications for the development of treatment programmes for anorexia nervosa, was the Minnesota starvation study conducted by Keys *et al* (1950). Keys reduced the intake of 36 young, healthy male conscientious objectors by 50% for a duration of six months in order to observe the effects of starvation. The men lost 25% of their body weight and starvation produced behavioural and emotional changes classic to anorexia nervosa.

The men soon recovered following a re-feeding programme and it was therefore inferred that many of the psychological features of anorexia were caused directly by the effects of starvation. Therefore, by re-establishing 'normal' weight, it was assumed that the psychological problems would also be resolved. The result of this study was that the findings from these male, psychologically healthy volunteers were generalized to treat anorectic populations in clinical contexts. Subsequently forced feeding of patients was often used to achieve weight gain in psychiatric and medical units (Wall, 1959).

Until the 1970's treatments were medically based and included nutritional, electroconvulsive and pharmacological techniques (Sesan, 1984). The growing awareness

of anorexia nervosa as a psychological disorder in the mid 70's brought about change in the context of the treatment from medical units to psychiatric hospitals. Typically the treatment consisted of behaviour modification, along with bed rest, high calorie supplements and supportive counselling following discharge (Garfinkel *et al*, 1985).

Behaviour modification enjoyed popularity in the 1970's and although reinforcement of eating through contingent rewards appeared to be very effective in the short term, Bruch (1974) drew attention to the dangers of such an approach. In the late 1970's a number of reports were published on the use of aversion therapy, such as Blue (1979) who discovered that a 15 year old anorectic made a dramatic improvement when her mother hit her with a stick when she vomited!

The efficacy of behaviour modification was not, however, challenged on ethical or moral grounds, but due to its limitations in representing a meaningful treatment of the complex nature of anorexia nervosa (Bruch, 1974, 1977). Furthermore, if anorexia nervosa is a symptom of the fact that the woman regards her life as out of control, and food restriction is her only means of gaining self worth, then such an enforcement of weight gain may lead to suicidal depression if the underlying difficulties are ignored (Lawrence, 1984).

Bruch (1962, 1973) heralded a shift towards psychotherapeutic interventions for anorexia nervosa with the aim of helping clients to achieve identity without relying upon eating control. As Button (1993) notes, it is this theme which runs through many other psychotherapeutic approaches in the eating disorders field.

Over recent years, multidimensional programmes in hospitals and specialist units have emerged which focus exclusively on the treatment of anorexia nervosa. Such programmes have tended to integrate behavioural management and individual, group and family therapy (Andersen *et al*, 1985). In a survey of specialist eating disorders services in the U.K., Robinson (1993) found that for anorexia nervosa, the most common approaches included individual therapy, either supportive, cognitive/behavioural or psychodynamic. Approximately half the centres surveyed used family therapy, and in a quarter of the centres drugs were used.

However, the majority of the programmes continue to focus on weight gain, weight stabilization and normalization of eating behaviours as primary goals, with secondary attention being paid to underlying psychological distress (Button, 1993; Sesan, 1984). The main reason for this, appears to be that many of the symptoms experienced are secondary to a state of starvation (Keys *et al*, 1950).

The majority of psychotherapeutic programmes rely upon cognitive-behavioural approaches to control eating disorder symptomatology, including contracts for weight gain prior to the onset of insight oriented treatment (Levendusky and Dooley, 1985; Roth, 1986). Wooley and Wooley (1990) (as cited in Sesan, 1984) stated that cognitive behavioural therapy (as applied to control symptoms) may be teaching women to suppress emotions, encouraging restriction of affect that is at the heart of the problem.

In terms of the outcome of developments in treatment programmes, the most promising finding is that mortality rates have dropped from around 19%, to around 5% (Hsu, 1980). In a review of four decades of outcome research on studies of anorexia nervosa, Steinhausen *et al* (1991) reported that follow up status showed that half of patients had a good or very good outcome, 30% had an intermediate outcome and 20% had a poor outcome. Hsu (1990), found that although weight improvement was common (between 50 and 60% were at 'normal weight' in this study), about two thirds were still intensely preoccupied with weight and dieting. Clearly, this highlights the dangers in using weight gain as the primary method for assessment of improvement, although with an increasing awareness of the psychological aspects of the disorder, studies have gradually moved to adopting weight and psychological criteria in assessing outcome.

## 1.3 The Patient's experience of treatment

With regard to the patients' own experience of treatment, Newton *et al* (1993) surveyed members of the Eating Disorders Association who volunteered to participate in a postal questionnaire survey of treatment acceptability. The response rate from the survey was good, with over half returning completed questionnaires. Counselling (which was differentiated from individual psychotherapy) and self help groups were regarded more favourably by participants than behaviour therapy. Interestingly, it is these interventions which are one of the least structured and cost effective forms of treatment. Approximately one third of the participants had experienced inpatient treatment, and of these 35% had dropped out of treatment. The most common reason given was the use of treatment aimed

at weight gain in the services. The most frequently cited area for improvement was increased opportunity to talk about the illness with someone who understands the difficulties.

In a recent study, Le Grange and Gelman (1998) elicited patients' (anorectics and bulimics) perspectives of treatment using a qualitative methodology. Interestingly most of the 21 participants reported improvement although the researchers' own formal assessments were more cautious. Participants identified psychoeducation, a supportive environment, challenging dysfunctional beliefs and behavioural strategies as helpful components of treatment. A significant minority of participants felt that causes of the illness were inadequately dealt with.

In a similar study, Noordenbos *et al* (1998) found that patients suffering from an eating disorder for ten years or more reported more negative experiences with treatment, especially behaviour therapy, tube feeding and admission to hospital. During or after these treatments participants said they often became depressed, sometimes suicidal and did not want to engage in any other kind of treatment.

In a study of recovered anorectic patients, Hsu *et al* (1992) sought to determine which factors facilitated recovery in order to gain a clearer understanding of this process. Factors related to the individual such as, 'personality strength', 'self-confidence' and 'being ready' were cited as important and 'being understood' with regard to the effects of the treatment. In terms of environmental/situational effects, most participants felt that getting out of a

destructive environment was a curative factor. Interestingly, participants who had received psychotherapy for their eating disorder, did not tend to perceive this as useful. Psychotherapy was only viewed as effective when there was unconditional acceptance and understanding of the eating problems.

There appears to be a gradual increase in research investigating the anorectic patients experience of treatment (for example, Newton, 1993; Noordenbos, 1998; Le Grange and Gelman, 1998). However it appears the opinions of patient's continue to be viewed cautiously. Research has suggested that self-reports are frequently distorted and inaccurate as anorectic patients are considered to be notoriously protective of their private experience (Vitousek *et al*, 1991). This issue remains a challenge for researchers who seek to find methods to overcome such distortion. The outcome of accessing patients' views is clearly invaluable to the development of appropriate treatments for the anorectic patient.

This literature review highlights the developments in treatment approaches in services for anorexia nervosa. To date, there remains no 'treatment of choice' for effective recovery from anorexia nervosa, unlike bulimia nervosa where cognitive therapies appear to be particularly effective (Fairburn *et al*, 1991). Furthermore, the ways in which patients and professionals conceptualise recovery may be quite different, leading to ambiguity in defining successful treatment.

Possibly one difficulty in the research has been the dual nature of the professional as a researcher and as therapist. Or, in cases where this has been more explicitly defined, that

the methods employed by the researcher are not conducive to gaining from the anorectics

an accurate understanding of the disorder and its meaning to the individual. Having

explored the developments in terms of treatment, it is now appropriate to address the issue

of drop-out.

## 1.4 Review of the literature on 'drop-out'

Drop-out from treatment services is common to a whole range of clinical services. A large

scale study by Sue *et al* (1976) found that 23% of cases commencing therapy at

community mental health centres dropped out after the first session, and almost 70% had

dropped out by the tenth session.

Defining the 'drop-out' is a troublesome task. Attempts have been made to distinguish

drop-out by temporal categorization, in terms of the timing of drop-out. Most studies for

example have defined the drop-out in terms of the number of visits made. However in

some studies the dividing line between 'drop-outs' and 'continuers' may be very fine

(Clinton, 1996).

Baekeland and Lundwell (1975) distinguished three kinds of patients which can be

subsumed under the term of 'drop-out';

a) the patient who fails to return,

b) the patient who refuses to return,

c) the patient who is expelled from a treatment program for lack of cooperation or poor

response to treatment.


In terms of the definition used for the purpose of this study, it was felt that it was important

to recognise the patients' decision to terminate therapy at any stage of the process.

Therefore 'drop-out' is taken to be any instance where the end of therapy was not based on

a joint agreement with the therapist. Drop-out would therefore incorporate cases in which

premature termination is either negotiated (i.e. the patient discussed their intention to leave

treatment) or cases where the patient failed or refused to return without discussing this with

the therapist.


Research in a variety of settings with a range of patient samples have attempted to

understand why patients drop-out of treatment. The studies conducted have primarily

focused on patient-specific variables such as social class, education, age, psychiatric

diagnosis, sex, marital and family status (Baekeland and Lundwell, 1975; Garfield, 1994),

and pragmatic issues such as transport difficulties (Hughes, 1995).


Lambert (1992) noted that reviews of outcome research indicated that 40% of therapeutic

change factors are linked with what the client brings to therapy. For example, Beutler and

Clarkin (1990) have catalogued a wide variety of client variables such as coping ability and

style, expectations, locus of control, ego strength, problem complexity, interpersonal

reactance and other personality patterns. However, as Garfield (1994) notes, such aspects

have had little impact or use to clinicians in changing the outcome of therapy.

Hughes (1995) conducted a small-scale study to investigate clients' reasons for terminating therapy. The majority were associated with some form of dissatisfaction with the sessions. These included;

1) clients' perceptions that the therapy was not progressing,

2) that therapy was not dealing with relevant difficulties,

3) and other difficulties pertaining to the skills and personality of the therapist.

An incongruance between the expectations of therapists and clients has also been suggested as another major reason for drop-out from therapy. Hughes (1995) suggested that clients may be looking for a quick cure for their difficulties, whilst therapists have different conceptualisations of improvement and the time required to achieve this.

Interactions between patient and therapist have often been explored in the drop-out literature. For example therapists who are perceived as 'aggressive' are particularly likely to precipitate drop-out (Sethna and Harrington, 1971). Much of the drop-out literature has arisen from studying drop-outs from group psychotherapy. Such studies may be helpful in separating therapist specific factors from the characteristics of the patient. For example Oei and Kazmierczack (1997), examined factors associated with drop-out in group cognitive behaviour therapy for depression using 131 participants. The results indicated that socio-demographic measures such as age, and measures of depressive symptoms did not discriminate drop-outs from completers. The therapists rating of client participation revealed that drop-outs participated significantly less than completers during the therapy sessions.

It is interesting to assess drop-out from treatments where the patient is likely to have little motivation to change. This would shift the emphasis away from the interactions within the therapeutic session, to a wider analysis of the meaning of the target problem. Cadsky *et al* (1996) investigated attrition from a male batterer treatment programme where it was perceived that most of the men would be attending therapy due to external pressures such as courts or partners. Of the 526 men recommended for treatment 41% attended a single treatment session, and only 25% completed the 10 week program. An interesting finding of the study was that one of the main variables associated with attrition was an incongruence between the client's self-identified problems and the targets of treatment.

Another fascinating area of the drop-out literature is the risk of mortality associated with non-compliance. Using intensive ethnographic interviews and participant observation in the urban slums of Northeast Brazil, Nations and Monte (1996) investigated non-compliance towards governmental efforts to control a cholera epidemic. Non-compliance with recommended regimens was found not to be a rejection of care by the poor, but more as a revolt against the accusatory attitudes of the elite. Using such methods, the researchers were able to unravel implicit meanings and metaphors about cholera as 'The dog's disease' which was associated with a history of social and economic inequality. Therefore, the dis-empowering image of cholera operated to blame and punish the poor and widen the social divide between communities. Such research highlights the dangers of fixing arbitrary labels to non-compliant behaviour and also highlights the value in understanding actions within the wider social sphere.

Anderson and Stewart (1983), describe common reasons for treatment refusal in treatment settings;

1. Opposition to the loss of self-determination.

2. Fear of vulnerability to a stranger's perceived reality, value judgment and skills.

3. Humiliation in being unable to solve one's own problems.

4. Fear of stigmatization of mental illness.

5. Lack of optimistic view of treatment outcome.

In terms of understanding drop-out from a theoretical perspective, it has been conceptualised in various ways and often closely linked with the major theories of personality and change. For example, psychodynamic theory tends to situate resistance almost exclusively with the patient. It is viewed as an expected and integral part of the therapy as clients repeat difficulties in the transference relationship (Messer and Warren, 1990). Kirmayer (1990) suggests that the therapist who labels a client's behaviour "resistance", attributes wilfulness, where the client may 'have only powerlessness and loss of control' (p.84).

Building on the work of Erikson, strategic therapists view drop-out as a consequence of efforts to maintain a consistent interpersonal stance. It is the therapist's insistence on moving in a direction that does not suit the current needs and capacities of the client that constellates a resistant interaction (Erikson, 1980). Therefore in psychotherapy, strategic therapists would aim to 'join' clients' positions to first support and then modify their stance (Marshall, 1976). There are similarities here with postmodern constructivist

therapies whose aim in therapy is to promote meaning and personal development, rather than correct presumed dysfunctions (Neimeyer, 1995).

A number of researchers have proposed that conflicts over dependency are a common reason in all therapeutic approaches for patients prematurely terminating therapy. 'Drop-out' has been construed therefore, as a means of maintaining a sense of control (Van Denburg & Van Denburg, 1992).

The research to date on drop-out from a range of services has yielded conflicting results. This may in part be due to the lack of a precise definition of drop-out. It may also be due to the varying research methods and procedures employed. For example, much of the research has focused on the specific characteristics of the patient in retrospective studies and has largely remained insensitive to the patient's view of the process of dropping out of services. This is unfortunate, given that knowledge of the patient's decision making process may have valuable implications for the implementation of treatment programs.

There is a conspicuous lack of research investigating service issues and assumptions seem to have been made regarding the quality of the service on offer, in which case, drop-out may have a very different meaning. In addition, it appears that few attempts have been made to address the function of the patient's symptoms and their meaning within their social context. Studies which have attempted to address this (such as Nations and Monte, 1996) have been rewarded with a more in-depth understanding of the meaning of non-compliance which in turn enables us to assess the wider influences on behaviour.

## 1.5 Drop-out and anorexia nervosa

It is well recognised that individuals with anorexia nervosa are frequently reluctant to present for treatment and require coercion, persuasion or threats from others (Engel and Wilms, 1986; Goldner, 1989). However it appears that despite the escalation in research into eating disorders generally, drop-out from services has received little attention (Mizes, 1998). The research that has been conducted estimates that approximately 50% of anorectics undergoing inpatient treatment terminate prematurely during treatment (Vandereycken and Pierloot, 1983; Button *et al*, 1997).

Refusal to engage in treatment poses profound dilemmas for eating disorder services. There is a body of evidence highlighting the negative effects of involuntary treatment, but there are also ethical considerations regarding the seriousness of non-intervention (Goldner, 1989).

There have been numerous theories proposed to account for this striking lack of motivation to engage in therapy. Idiosyncratic characteristics deemed to be specific to the anorectic are frequently linked with drop-out from treatment services. Goldner (1989) suggests that individuals with anorexia nervosa may have specific characteristics which exacerbate each of the general reasons for treatment resistance previously outlined by Anderson and Stewart (1983).

For example, the pervasive sense of ineffectiveness identified by Bruch (1978) is believed to be accompanied by a deep shamefulness which would amplify the individual's resistance to seeking help for their problems. Anorectic patients have been found to experience less trust in interpersonal relationships (Garner *et al*, 1983), and distortions in thinking have been recognised which affect their conceptual, perceptual and decision making abilities (Garner and Bemis, 1982; Dritschel *et al*, 1991; Butow *et al*, 1993). Their lack of feeling and understanding for their condition is also thought to contribute to poor motivation (Mesters, 1981, as cited in Engel and Wilms, 1986). Indeed, one of the major hurdles which was identified in the historical descriptions of Lasègue (1873), is that patients do not regard themselves as having a problem (Blake *et al*, 1997).

If one views anorexia as a 'solution' to developmental, psychodynamic, familial, or societal crises then resistance might be seen as a comprehensible response to a perceived threat to the individual's self-esteem and identity (Goldner, 1989). For example Bruch (1978) and Orbach (1986) identify the intense need for self-determination which drives the anorectic. The drive for self-determination results in the anorectic rejecting treatment since it appears to involve relinquishing control over one's private world. This notion is supported by Bliss (1982) who surveyed the perceived advantages of anorexia nervosa and discovered that 73% cited self control as an asset. As Bruch (1985) suggested, in urging the anorectic patient to co-operate with treatment and gain weight, we are asking her to give up what she regards as a 'perfect solution'.

Several authors have highlighted the importance of meta-cognitions (beliefs and actions concerned with the regulation and interpretation of a person's own cognitions) in the maintenance of anorexia nervosa (Wolff and Serpell, 1998). Patients with anorexia nervosa generally express positive beliefs about their condition (Serpell *et al*, 1999) and these pro-'anorexia beliefs' are thought to maintain the disorder and enhance resistance to treatment (Wolff and Serpell, 1998).

Using Kelly's (1955) personal construct approach, Button (1983) demonstrated that anorectic women have trouble changing their eating behaviour because they have highly defined, negative and overly constricted constructs that form the basis of the reasoning behind not becoming normal in weight. Marsh and Stanley (1995), attempted to explore some of the personal constructs of anorectics and contrast the way they viewed themselves in relation to others before and after treatment. The results suggested that the anorectic woman may be very aware of the negative characteristics that society generally expects her to display. However, these do not 'mesh' with the characteristics that she considers central to her sense of self. Therefore the socially imposed interpretation of negative qualities directly conflicts with the internal positive emphasis on the disorder. Furthermore, treatment failed to change such construing and it is suggested therefore, that resistance in treatment may be attributed to the inability of the anorectic to construe the undesirable features in a manner consistent with their sense of self.

Other researchers have turned their attentions away from characteristics of the patient, to investigate the features of the therapeutic relationship. Clinton (1996) conducted one of

the few research projects to investigate the issue of drop-out from eating disorder services. By assessing 60 patients and 7 therapists he ascertained that drop-out was related to a lack of congruence between the therapists and the patients' expectations of potential treatment interventions. In particular, drop-outs had significantly greater expectations of being helped by insight-related interventions than their therapists. Measures relating to the patient's degree of eating disorder pathology, general psychopathology, therapist and treatment specific variables did not distinguish drop-outs from those who completed a course of treatment. However, a limitation of this study was that patients and therapists were interviewed at different times within the research process and therefore the therapists' treatment results may have influenced their ratings of interventions associated with drop-out.

In a qualitative study of health care professionals, Jarman *et al* (1997) examined subjective understandings and experiences of treating young people with anorexia nervosa amongst 5 clinicians in a multi-disciplinary child and adolescent team. A theme of 'control' emerged as central to understanding treatment although this construct was multi-faceted and engendered multiple meanings for the therapists. For example, in terms of the client's desire for control, relationships with the self (intra-active control) and others (inter-active) control were identified. The particular meaning given to the child's desire for control impacted upon the treatment the client received and how the therapist experienced this process.

If anorexia nervosa is viewed as a strategy to stay 'in control', then treatment would clearly present a significant threat to that control (MacSween, 1993). Therefore, several researchers have suggested that this therapeutic impasse may be overcome through the use of specific therapeutic strategies which enable the client to retain maximum control over their food intake (Jarman *et al*, 1997).

In a paper titled, 'Winning the war without having to do battle', Sallas (1985) drew attention to issues of power and control which are encountered by therapists when treating individuals with eating disorders. Sallas (1985) equated resistance to an association of the symptom behaviours with a perception of being in control and relinquishing them with being out of control. Therefore, she advised therapists to 'establish the therapeutic relationship in such a way to avoid, reduce or eliminate the emergence of power struggles' (p.445). For example, underlying issues should be addressed so that the therapist has an understanding of the ways in which the symptom behaviours serve each client as a coping strategy. The therapist should then emphasise that their goal of wishing to remain in control is appropriate, but the means in which they have chosen to achieve this goal are inappropriate.

Garner and Bemis (1982) support a focus on the function of anorexic symptoms as often the negative aspects of the illness are illuminated without exploring the positive reinforcers maintaining the disorder. Techniques such as encouraging the patient to write a letter to the anorexia addressing their illness as a friend and an enemy can explicate positive and negative aspects of the disorder (Treasure and Ward, 1997).

More recently, developments in the field of addictions (Miller and Rollnick, 1991; Prochaska and DiClemente, 1992), have increased our understanding of enhancing motivation for change in the treatment of eating disorders (Blake *et al*, 1997). Prochaska and DiClementes' trans-theoretical model proposes that different processes operate at the various stages of motivation for change. This has clinical implications in terms of providing the appropriate treatment focus for individuals at particular stages of change.

Blake *et al* (1997) discovered that half of the 51 anorectic patients in their study were not ready to change their behaviour when first presenting at the clinic, in comparison with 80% of bulimics. The task of the therapist is therefore to assess the patient's position in the cycle of change, (for example through questionnaires, Engel and Wilms, 1986) and use strategies appropriate to this stage (such as assessing the pros and cons of anorexia nervosa in the early stages, Wolff and Serpell, 1998).

Based on such literature Vitousek and Watson (1998) recently outlined four themes deemed to be crucial in engaging treatment-reluctant eating disorder clients. These were the provision of psychoeducational material, examination of the advantages and disadvantages of symptoms, use of experimental strategies, and exploration of personal values.

It is surprising that there have been very few studies specifically addressing the issue of drop-out in anorexia nervosa given that it is a psychiatric disorder with a potentially fatal outcome. The research that has been conducted, again, has tended to focus on patient

variables. The effect appears to have been to consolidate the notion of the anorectic patient as especially 'resistant' and 'manipulative' without fully understanding the meaning of this resistance. Indeed the meaning of drop-out from eating disorder services may significantly overlap with drop-out from other generic services. However, the clarity of the anorectic patients' suffering in terms of the symptom of weight loss, seems to have prevented us from attempting to understand the function and the meaning of the disorder and how this contributes to drop-out.

## 1.6 Summary of current debates

This critical review of the literature has drawn attention to the changing conception of anorexia nervosa and the influence of wider political, social and cultural developments on its definition. It can be seen that much of the early research and 'discourse' about anorexia nervosa continues to have an influence on both our conception of the disorder as a psychopathology, and subsequently the 'medical' based interventions aimed at treating the symptomology of the disorder.

The current theories and conceptualizations of drop-out reveal the multiple ways in which researchers have attempted to explain this perplexing and concerning issue. There appears to be a focus on the specific characteristics of the patient in both the eating disorders and general psychotherapy research literature. This focus in the literature has situated the responsibility for drop-out with the patient and has reinforced a focus on the search for idiosyncratic features related to the pathology of the disorder. As the source of the problem

is located at an individual level, treatment approaches have been almost exclusively focused on intrapersonal change.

Although this literature is useful in increasing awareness to the possible difficulties which might arise within therapy, it appears to have had little impact on the effectiveness of treatment interventions. This is unsurprising given that patient-specific factors (such as social class, education and age) are possibly the least accessible elements to change in psychotherapy (Clinton, 1996).

Such an approach neglects the influence of the wider contexts and interactions already known to be particularly influential in the predisposing factors of anorexia nervosa. In addition conventional methodologies as applied to understanding drop-out have tended to ameliorate differences, in their search for specific factors, when in fact, as clinicians it would be simplistic to be treating a complex and multifactorially determined disorder such as anorexia nervosa in this way. Furthermore, the current focus on the anorectic patient and the methodologies utilized in this endeavor may reproduce the current conceptualizations that restrict us from exploring alternative meanings and conceptions.

It is therefore argued that the current literature does not adequately address the subtle differences of experience and meaning of treatment and drop-out from the eyes of those who actually experience the disorder. It is advocated that there is a need to understand the complexity of the process of drop-out from eating disorder services in order to gain a

clearer understanding of the possible links between the factors previously highlighted in the literature.

## 1.7 Research questions and aims

The purpose of this research is to develop an understanding of the meaning of drop-out from services for individuals with anorexia nervosa. In doing so, the research aims to give expression to the views of patients who have dropped out of services. It will address the significance and meaning an eating disorder holds for the individual and also the implications that therapy has on changing this meaning.

The aim of this research is not necessarily to dismiss or disprove the significant contributions of research to date, but to integrate and understand them from the patient's own perspective. In assessing the patients' view of their treatment and the meaning of their disorder, this research would aim to foster more facilitative explanations of drop-out, and in doing so, enhance understanding of pertinent issues in the context of treatment. Ultimately, such knowledge could possibly have organisational and clinical implications in the treatment of anorexia nervosa.

## 1.8 Qualitative research

Given that the aim of this project is to explore the experience of drop-out from services, methods are required which are conducive to a full exploration of such diversity and

experience; one which allows us to capture the meaning of actions and allow for flexibility over time, culture, and social contexts.

There has been a great deal of interest in the debate of quality and quantity in social science methodology over recent years. Qualitative research concerns itself primarily with understanding process, rather than outcomes or products. It therefore lends itself to non-numerical procedures of data collection, such as semi-structured interviews, observation and field notes.

It is a particularly useful method for exploring meaning in terms of how people make sense of their lives, actions, events, experiences and structures of the world. The aim has been to understand such issues through the eyes of particular participants and remain sensitive to the complexities of behaviour and the contexts in which they occur (Henwood, 1996). The qualitative process is inductive in that the researcher builds abstractions, concepts, hypotheses and theories from the accounts provided by participants.

A qualitative method would be a more appropriate method for understanding the questions and areas of interest outlined for this research. As previously mentioned, there has been a paucity of integrative theoretical understanding of the concept of drop-out in the research and qualitative research lends itself to such areas where theoretical understanding of the topic is in its infancy. Although theoretical understanding of anorexia nervosa has a long history, there is a need to address the complexity of the disorder, rather than search for simple solutions. In addition, one of the central features of this research is regarding the

variety of meanings attributed to the process of drop-out from services. Again, a feature central to qualitative research is its usefulness in accessing meanings (how people make sense of their experiences) and also its concern with 'process' rather than outcomes or products (Creswell, 1994).

## 1.9 Expectations of this study

As this research is qualitative in nature and with a primary aim of exploring meaning, specific hypotheses and questions are not considered to be appropriate for this study. What we may expect from this study, and given the issues of interest previously mentioned, is a range and variety of meanings about drop-out, which will hopefully capture social, cultural and psychological meanings of the process of drop-out and also how these aspects operate and interact. In the following chapter, I shall be setting out the specific means of achieving this.

**METHODOLOGY**

## 2.0 Overview of chapter 2

As outlined in chapter one, the aim of this study is to explore the various meanings that

patients diagnosed with anorexia nervosa attribute to the act of 'dropping out' of services.

It was argued in the previous chapter, that to fully explore the variety of meanings attached

to this act, a method is required which allows the researcher to explore this issue in relation

to social, historical, cultural and psychological contexts. A method is required which

allows the researcher to explore the minute details and differences in the accounts that

participants describe.

This chapter will begin by developing the specific epistemological framework (or

considerations regarding the nature of knowledge and legitimate inquiry) used to guide the

methodology of this research. It will be argued that for the purpose of this study,

traditional methodologies would be inadequate. A social constructionist approach (Berger

and Luckmann, 1966) is based on the assumption that people construct their own world.

Researchers adopting such an approach would doubt that objective knowledge exists, but

rather that there are multiple realities of viewing the world which are relative to culture,

location and history (Holloway, 1997). This approach will be advocated as a theoretical

model for understanding the research process in this study as it provides a more appropriate

framework for addressing the meaning of experience and behaviour in context and in its

full complexity.

The differences between realist (the belief in an objective reality) and social constructionist frameworks will be explored and will lead to a discussion of the particular method utilized by this study for the generation and analysis of data. To this end, a social constructionist revision of grounded theory will be discussed and applied to the research design and analysis in this study. This chapter will close with a discussion of methods to enhance the quality and evaluation of qualitative research and explore how they have been applied in this study.

## 2.1 Epistemological debates in social research

Epistemology is the theory of knowledge (Holloway, 1997). It represents a 'world view' that helps to define the nature of the world, ones own place and possible relationships within it (Guba and Lincoln, 1994). There is no way of establishing the ultimate truthfulness of such theories. However, epistemological considerations are central to the research process as they help to define the relationship of the researcher to the participants.

*Realism in contrast to social constructionism*

Social sciences have been characterized by two broad approaches to collecting data. On one side, there are researchers who could be compared to scientists in the way they conduct their research. This is labeled as a realist or positivistic orientation whereby the researchers aim is to develop objective truths about the real world (Warner, 1996).

Realism is the belief that a reality exists independent of the perceptions of human beings and an assumption of objective reality (Holloway, 1997). The researcher and participant

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are assumed to be independent entities and the goal of the method is to limit wherever possible the effects of researcher bias (Henwood and Pidgeon, 1992).

The positivistic researcher's aims are to discover the laws which govern the relationship between causes and effects (Banister *et al*, 1994). It is such a philosophy that traditional quantitative research has based itself upon.

The alternative argument proposes that possibly too much is lost when we attempt to screen out confounding variables and when material is quantified. Therefore an argument has developed for an alternative philosophy in social research. Social constructionists recognize that research is frequently structured by personal and political interests, which need to be explored rather than hidden away. It is based upon the assumption that our experience and knowledge of the world is constantly being produced or constructed by people in everyday interaction with each other (Burr, 1997). This philosophy suggests that individuals and groups view the world differently which are relative to culture, history and location.

Proponents of this approach view human beings as constantly changing and therefore, within the research study itself, the researcher and participants interactions produce the findings together. The aim of inquiry therefore is to understand the constructions that people hold whilst remaining open to new interpretation as people change and develop (Guba and Lincoln, 1994).

It is important, however, to recognise the similarities as well as the differences of the approaches. For example as Henwood and Pidgeon (1992) suggest, 'Qualitative and quantitative research procedures are but different forms of the analytic practice of re-representation in science, in that both seek to arrange and rearrange the complexities of raw data' (p.17). In addition Henwood and Pidgeon (1992) suggest that researchers should always bear in mind that methods are not so much valid in and of themselves, but rather will be more or less useful for particular research purposes.

*Epistemology of this study*

A social constructionist approach to understanding the research process and production of data appears to provide a more appropriate framework for addressing the diversity of meanings attached to the experience of drop-out from services. Such an approach has the advantage of enabling researchers to challenge constructions of people or groups that we may feel have oppressive effects and instead begin to develop constructions which are more facilitative. For such reasons it is this school of thought which has primarily guided the assumptions underlying this study.

*The researcher*

If researchers operate within the constructionist paradigm it is important to be aware or demonstrate a reflexive engagement with ones own history, values and assumptions as well as the relationship with participants (King, 1996). The aim of the inclusion of this section is to bring to attention some of my own background in the hope that this will increase the reader's awareness of the possible interactions between researcher and participant.

This research was conducted in my final year of training as a clinical psychologist. Prior to training I had worked for two years in a variety of settings within the NHS. This was my second research project conducted specifically addressing the area of eating disorders. The previous research was submitted for a B.Sc. Hons in Social Psychology and was a quantitative study assessing the impact of the environments of a ballet school and secondary comprehensive school on dietary restraint. The current study was the first project conducted using a purely qualitative methodology.

*Researcher's assumptions*

My own professional experience within clinical psychology had some impact on the choice of topic area researched and the development of the research questions. During my first clinical placement in an adult specialty my casework involved the assessment and treatment of three females diagnosed with anorexia nervosa or partial syndrome anorexia nervosa. The research question was partly developed from my own experience of drop-out by patients with anorexia nervosa and from the difficulties I experienced in helping patients to overcome resistance to changing their eating behaviour.

As previously mentioned I completed a social psychology degree course at Loughborough University. This course had some impact on my understanding of social systems and the context of environments in relation to psychological distress. In addition to this, there was a strong qualitative research influence within the department, such as developments in

discourse analysis by Jonathan Potter (Potter and Wetherell, 1987) which had already

opened my awareness to the benefits of such approaches.

Within the context of clinical work, my particular interests lie in cognitive analytic therapy

and the application of attribution theory to clinical problems. Throughout the study my

expectations, assumptions, emerging themes, and general thoughts and feelings about the

research were recorded in a diary. The aim of this was to enhance my awareness of issues

regarding reflexivity, and the importance of remaining aware of one's own decision-

making processes.

Extract from research diary;

6th November 1998

*I am beginning to recognise the privileged position the researcher has in understanding the participant's situation, in comparison to a therapist. For example, being able to just listen to what is being said, without having another agenda of 'How on earth do I deal with this?' really enables you to 'hear'. It was interesting that after today's interview, participant 3 mentioned that she would have felt more willing to stay in the service if her initial appointment had been like the interview. I wondered whether she would have felt the same if I too had had an agenda about how I would be attempting to change her eating disorder.*

10th December 1998

*Today's interview raised some really interesting issues for me. I had been wondering why there seems to be an emphasis on symptoms in the eating disorder services, and I think participant 5 helped me to understand this. Most of the participants I have seen have looked underweight, but not looked as though the disorder was at a life threatening stage. However participant 5 is just 4 stones ten pounds. I found it so difficult sitting and listening to her say that she felt fat and could totally understand that as a therapist/parent/friend, I would automatically want to 'save' this woman and I would save her by trying to solve the observable problem of 'weight'.*

> 11<sup>th</sup> January 1999
>
> *I am beginning to realize that conducting this research has had an impact on my clinical work. In one of my therapy sessions today I sensed that the client was ambivalent about change. Normally I would have spent time outlining the model I intend to use and justifying its effectiveness with depression. However, I found myself asking questions about the way in which depression is functional for him. I think we were both surprised to find that by exploring this, we could identify some very 'functional' reasons for remaining depressed; particularly with regard to reciprocal roles and the effect that change would have on his partner.*

Emerging themes were also discussed within a qualitative support group. The group consisted of six trainee clinical psychologists who were all conducting qualitative research in the final year of their training. On occasions the group was facilitated by an experienced qualitative researcher who provided guidance and advice regarding methodological issues. The aim of the group was to provide support, advice and also a forum for others to challenge and help define the emerging theory.

## 2.2 Grounded theory

Grounded Theory was developed in 1965 by two sociologists, Barney Glaser and Anselm Strauss, during their investigation of the institutional care of the terminally ill (Glaser and Strauss, 1967). The term refers to the grounding of theory in experiences, accounts and local contexts. It also refers to a method which involves a logically consistent set of data collection and inductive analytic procedures aimed to develop theory (Strauss and Corbin, 1990; Charmaz, 1995).

*Why Grounded Theory?*

Pragmatic and epistemological considerations informed the choice of qualitative approach in this study. Grounded theory is particularly suited to the study of local interactions and meanings as related to the context in which they actually occur (Pidgeon, 1996). Therefore, this method is considered to be particularly useful for psychologists who wish to study the varied groups of people with whom they work. Grounded theory methods are designed to study process and so allow the researcher to explore the development, maintenance and change of individual and interpersonal processes (Charmaz, 1995). Grounded theory also provides explicit skills and techniques that help in the generation of theory (Strauss and Corbin, 1990; Charmaz, 1995).

*Features of grounded theory*

There are a number of distinct features of the data analysis using this method. These include;

- The generation of low level categories to describe the features of the data, and which closely 'fit' the data.

- Creation of definitions and linkages between categories at different levels of abstraction.

- Making constant comparisons between cases and categories in order to fully explore the complexities of the data and sensitizing the researcher to similarities and differences.

- Theoretical sampling. This involves the active sampling of new cases to elaborate on the account and ultimately extend emergent theory. An important aspect of theoretical sampling is the exploration of negative or deviant cases which do not fit the emerging conceptual system. This serves to challenge assumptions and categories.

*Reformulation of grounded theory*

A number of criticisms have been levelled at the original Glaser and Strauss model of grounded theory. For example, it assumes that theory simply emerges or is 'discovered' from the data, without recognizing that it may be pre-interpreted in terms of existing concepts and theory (Pidgeon, 1996). Such implications align grounded theory to a more positivist epistemology which assumes that social and psychological relationships exist objectively (Pidgeon, 1996). Here, there is an apparent contradiction between an inductivist approach to analysis and encouraging the researcher in the interpretive process of generating new theory.

This critique has prompted revisions in the grounded theory approach. Charmaz (1990) advocated a constructionist version of grounded theory, whereby researchers must have a perspective from which they seek to build their analyses, but without merely applying it to new data. The researchers perspective would include interests which guide the research questions, a philosophical stance or school of thought and also one's own personal experiences (Henwood and Pidgeon, 1995).

Researchers such as Charmaz (1990) suggest that in reality, discovery represents an interplay or 'flip-flop' between ideas and research experience and, as Pidgeon highlights, may more appropriately be described as theory generation than discovery.

## 2.3 Design

This study adopted a qualitative methodology, and more specifically a social constructionist revision of grounded theory analysis. Raw data were derived from interview transcripts and written accounts (or narratives) provided by participants. For an outline of the time scale of the research, refer to appendix 2.

### *Participants*

A total of 8 females took part in this study. Seven participants were interviewed of whom 4 submitted narratives of their experiences. Participant number 8 submitted a narrative but she did not attend for interview. For a summary of the clinical characteristics of each participant, refer to appendix 3. The number of participants reflected the in-depth nature of qualitative research and the rich and detailed amount of data which can be gained from a small number of interviews.

### *Research context*

All of the participants had attended a local specialist service for adults with eating disorders which receives approximately 200 new referrals each year. The service is staffed by a multi-disciplinary team with the aim of providing comprehensive assessment, advice and therapy to patients who present with problems along the eating disorders spectrum.

Typically patients are assessed for between 1 and 3 sessions. If treatment is mutually agreed to be an appropriate option, the patient is then placed on a waiting list for therapeutic intervention. In cases where weight is particularly low, the individual is

quickly designated a therapist. Therefore, patients diagnosed with anorexia nervosa are often seen earlier than patients diagnosed with bulimia nervosa. Approximately four fifths of patients are treated on an outpatient basis, the remainder through inpatient and day patient facilities (Button *et al*, 1997). The treatment approach is predominantly psychotherapeutic with concurrent physical and social interventions where appropriate (Button *et al*, 1997). The therapeutic work with anorexia nervosa is relatively long term with a mean duration of contact around 22 months. A patient information leaflet is included in appendix 4.

Anorexia nervosa is generally construed by the service as a person's way of maintaining a sense of control. When faced with difficulties which are deemed uncontrollable, food, weight and eating are means of gaining a sense of control which may then help the individual to deal with the other problems in their life. There is a dual emphasis in the treatment on monitoring of weight gain and food intake alongside psycho-therapeutic interventions, both of which are conducted by the same professional.

Dependent upon the severity of weight loss, individuals are seen on an outpatient basis and are assigned a therapist whom they would initially meet with on a weekly basis. The type of therapy varies considerably depending upon the theoretical orientation of the therapist. Therefore, cognitive-behavioural, personal construct and psychodynamic approaches are all offered by the service.

If the individual's weight is particularly low, or outpatient treatment is insufficient in achieving weight gain, the patient may be admitted as an inpatient to an acute admission psychiatric ward. The philosophy of the 'regime' (the label given to the inpatient treatment approach) is for the patient to hand over control of food, weight and eating to the staff, thus helping them to begin to deal with the other problems in their life. Boundaries are enforced to ensure that the patient feels safe enough to change. Efforts are made to ensure that compulsory treatment is avoided by enhancing collaboration between patients and professionals regarding the inpatient stay.

Each patient is given a detailed diet plan with the aim of gaining approximately one kilogram per week (or 2lbs), until the patient reaches the allotted target weight. In terms of therapeutic input, inpatients receive weekly individual psychotherapy and also attend a day programme (consisting of various group and activities, e.g. assertiveness groups, art therapy, relaxation, cookery) once weight gain is established.

Recent research by the service (Button *et al*, 1997) examined progress and service consumption of 100 referrals to the unit. Approximately half of all patients dropped out of treatment. Three-quarters of the patients surveyed felt that they had improved and there was a reduction in the percentage of cases meeting criteria for anorexia nervosa from 62% to 33%.

*Criteria for Inclusion*

The sample selection was criterion-based, in that all participants had to fulfil the following criteria;

1) DSM IV criteria for anorexia nervosa or partial syndrome anorexia nervosa (i.e. patients who displayed weight control strategies typical of anorexia nervosa, but with no amenorrhoea and/or body mass index was between 17.5 and 20).

2) Drop-out occurred within two years of the start of the research (i.e. between September 1996-September 1998).

*Exclusion criteria*

1) Where patient was known to have a co-morbid psychotic disorder.

2) Where patient was currently receiving some other form of therapy or treatment from another service.

*Description of participants*

Table 2.0

| Participant Number | Age at research | Weight at assessment | BMI at assessment | Stage of drop out | Diagnosis |
|---|---|---|---|---|---|
| 1 | 22 | 44kgs | 15.4 | 2 therapy sessions | PSAN |
| 2 | 32 | 46kgs | 19.2 | Assessment | PSAN |
| 3 | 23 | 42kgs | 18.5 | Assessment | PSAN |
| 4 | 21 | 47.5kgs | 16.5 | 1 year of therapy | AN |
| 5 | 22 | 32.8kgs | 14.5 | 12 therapy sessions | AN |
| 6 | 43 | 44kgs | 17.6 | Assessment | PSAN |
| 7 | 22 | 44kgs | 17.4 | 4 therapy sessions | AN |
| 8 | 21 | 38kgs | 15.7 | 7 therapy sessions | AN |

Key to table 2.0:

PSAN = Partial syndrome anorexia nervosa

AN = Anorexia nervosa

BMI = Body Mass Index

Table 2.0 outlines the clinical information on each of the participants taken from the patients' records at the eating disorder service. The diagnosis of anorexia nervosa or partial syndrome anorexia nervosa was made by the professional conducting the initial assessment using standardized assessment tools such as the Eating Disorders Inventory (Garner *et al*, 1983), clinical interview and DSM IV diagnostic criteria (American Psychiatric Association, 1994).

*Procedure*

*Recruitment of participants*

Ethical approval was sought from the Leicestershire Ethics Committee, and approval was granted on 10th September 1998 (see appendix 5). Data were collected in the months of November and December 1998.

Potential participants were selected from records at the local eating disorders service. Patients fulfilling the criteria previously outlined were sent a letter containing information about the aim and nature of the study (see appendix 6), a consent form (see appendix 7) and a covering letter from the director of the eating disorders service (see appendix 8).

They were asked if they would be willing to attend an interview which would focus on their experience of treatment for their eating disorder and possible reasons for their drop-out. They were also asked if they would be willing to write a short account or story about their experiences prior to interview.

A total of 28 patients (who fulfilled the selection criteria previously outlined) were contacted regarding this study. Approximately 50 patients fulfilled the inclusion criteria for this study. However not all were contacted as they were already involved in other research projects. Twelve participants responded; two of whom were only able to complete a narrative as they had since moved out of the country. One participant who initially agreed to participate in the study, was subsequently re-admitted to inpatient care and did not wish to proceed with the research. The data collection was terminated after receiving five narrative accounts and completion of the seventh interview, as it was felt that there was a saturation of new themes (i.e. the latter interviews failed to uncover new ideas).

*Confidentiality*

The sensitive nature of the data collected highlighted concerns around the confidentiality of the information and the subsequent presentation of the results. In quantitative research, the transformation of personal experience into numbers, means that it is relatively easy to guarantee anonymity (McLeod, 1996). In contrast, the nature of qualitative research makes it much more difficult to conceal the identity of participants, as accounts are unique to individuals.

In terms of data collection, all participants were asked for their consent for the interview to be tape-recorded, and they were offered their own copy of the-tape recording. All participants gave consent for the interviews to be tape-recorded, and none of the seven participants interviewed wished to be sent a copy.

With regard to data management, any identifying names (of places, family, friends or professionals) were excluded. In interview 2, a large section has been removed from the typed transcript as it was felt that this was not directly relevant to the research questions, and it contained a substantial amount of personal information which may have jeopardized the anonymity of this participant.

*Narratives*

There was a dual aim of asking participants to complete a narrative account of their experiences. Primarily, the narrative provided an alternative source of data which allowed the researcher to triangulate the data sources (i.e investigate the research question using different strategies), and thereby increase the validity of the study. This is described in more detail in section 2.4 (assessment of qualitative research). The narrative also allowed the participants to guide important issues so that these could be explored in more detail in the interview.

Participants were provided with the title of the narrative, "My experience of treatment for my eating disorder", and they were asked specifically to focus on the process of drop-out from services.

Five narratives were received from participants, which were self-selected in terms of whether the participant was willing to provide a written account of their experiences.

*Interview Guide*

A semi-structured interview seemed appropriate for this research study, as it allowed the specific research agenda to be addressed whilst remaining open and flexible to new ideas. This was particularly important in the latter stages of data collection when specific questions could be asked regarding the emerging themes.

An interview schedule was developed from the early narratives completed by participants (see appendix 9). This was then revised to accommodate emerging themes from written accounts as they were received. The guide also contained areas of interest from the author's personal experience of client drop-out and current theories within the literature.

The guide was flexible and aimed to explore the process of treatment by focusing on the following areas:

1) Background information about the onset of their disorder and how they came into contact with services.

2) The initial assessments and thoughts and feelings about engaging in treatment.

3) Perceptions of the disorder

4) Expectations of treatment, the type of treatment received and their evaluations of this.

5) The process and experience of dropping out of services.

6) Improvements and unmet needs

7) The present day and effects of dropping out.

There is an emphasis in grounded theory on the simultaneous collection and analysis of data. Throughout the course of data collection, the interview schedule was revised to take account of emerging themes. For example later on specific questions were added such as;

Why do you think your eating disorder did not seem problematic for you?

How did you feel about the diagnosis of an eating disorder/ anorexia nervosa?

What would it have meant to acknowledge the eating disorder as a problem?

Participants were not weighed at interview, nor were they asked directly about their weight. A clinical judgement of their weight was not considered to be central to the aims of this study. However, a subjective interpretation of their current weight was made as it was felt that this was beneficial to the reader in assessing the interaction between researcher and participant. This is discussed in the clinical characteristics of the participants (appendix 3).

*Interview Procedure*

The location of the interviews varied depending on the wishes of the participant. Therefore, some interviews were conducted at the participants' own home (n=3) and others at the hospital (n=4). The interview commenced with a warm-up phase where individuals were asked general questions about their work, hobbies etc. Issues specific to the interview such as confidentiality and estimated time of interview were discussed before providing the participant with a brief outline of the topic areas to be covered (see appendix 10).

The interviews lasted between one hour and two and a half hours in duration. The interview closed with a 'wind down' section which was intended to gain participant's general views on the research and discuss any concerns about the interview.

*Data Management*

All the participants provided consent for the interview to be tape-recorded. This allowed each interview to be transcribed verbatim, therefore ensuring that no detail was lost from the interview. Each transcript and narrative was given a numerical label in terms of the sequential order of when it took place in the research process and numbered line by line. Transcripts were identified by I (for an interview) or N (to denote a narrative). For example a section of text referring to the $26^{th}$ line of the second interview was identified by I2:26. Any lengthy pauses in the transcripts were identified with the following symbol (.). In some interviews sections of the tape recording were inaudible and therefore missing sections were identified in the transcripts by XXX. In one interview, (I7), the participant's mother was present throughout the interview, and her words have been typed in italics to distinguish her from the participant. In this instance, the mother's comments were not coded directly, but they were used to inform the emerging theory. Any identifying details such as names were replaced with stars to protect identification of the participant. The full transcripts are bound separately (see addendum 1).

*Data analysis*

*Organization of data*

Broad areas referring to the process were initially identified. These were;

- the onset of the eating disorder

- initial contact with services

- treatment

- drop-out

- life after drop-out.

Transcripts were divided into the relevant stage of the process by literally cutting various sections and placing them in the relevant folder titled as above. The transcripts within each folder were read repeatedly to gain familiarity with the raw data.

*Open coding*

The next step was to re-organise the raw data by cutting the transcripts into sections of meaning units (i.e sections of text which appeared to be linked by similar themes). Data analysis proceeded after each interview by placing an index card with a tentative label for the emerging concepts in each of the folders. Similarities and diversities were compared by asking questions of the data such as, 'What is going on here?', 'What does this represent?'

Similar concepts were grouped together to form categories. These categories were then expanded by developing properties i.e. characteristics of a category. Such properties are frequently located along a continuum (dimensions of properties).

This method of data analysis appeared to fit the data more appropriately than the line by line analysis advocated by Strauss and Corbin (1990) as it allowed the researcher to locate

the emerging concepts within the treatment process, and monitor how they changed or were

defined over time.

Example of an index card

<div style="border:1px solid black;">

**NOT FITTING IMAGE OF ANOREXIA NERVOSA**

Folder:  Initial contact with services

I2: 662          Surprise at label.  Felt she did not conform to popular image of
                an anorectic patient.
I3:320          Anorexia nervosa associated with weakness.
I4: 77          Expectation that she would be laughed at on commencing
                therapy for being too fat.
I5:285          Felt huge in comparison with other patients.
I6:414          'Stigma' attached to label of anorexia nervosa.
I7:47           Label perceived as an insult because she did not feel 'thin
                enough'.
N4:29           Felt she was time wasting because she did not fit the anorexic
                image.

Possible links with:

Ambivalence about change
Admission versus acceptance of problem
Covert help seeking
Denial
Comparison with psychiatric patients

</div>

*Axial coding*

The second stage of the coding was to consider the relationship between categories and

attempt to integrate emerging themes.   This was achieved through the use of;

1) memo writing

A written account of comments on the research process, hunches, directions to explore and

modifications of categories.

Example of a memo;

---

**Help Seeking**

There appears to be a stage in which the eating disorder begins to lose its function as a coping strategy. This is linked to;

a) A change in behaviour in order to achieve the same sense of achievement and control over the disorder. This may include the onset of bulimia which is associated with a sense of feeling out of control. Also the coping strategy is challenged when the individual is no longer able to overcome the physical symptoms of the disorder such as weakness and fainting.

b) Others reactions to visible weight loss. The 'public' nature of the disorder ensures that other people can observe the problem in a more tangible way than many other psychological disorders. It therefore evokes extreme reactions such as force feeding and threats which eventually result in the individual isolating themselves or seeking help under coercion.

---

2) Writing definitions of categories.

---

**Partial Recovery**

This category concerns the individual's experience of a continued battle with the disorder following drop-out. The term partial is used as it refers to the transitory nature of the disorder. Restriction of food intake continued to be used as a coping strategy under stressful circumstances. Therefore the course of the disorder could change on a daily basis dependent upon environmental, situational and interpersonal stresses.

Also, the term partial refers to the integration of the disorder into ones self-identity. It had become a 'friend' and provided safety and comfort for the individual.

The treatment approach in combination with others reactions to the disorder seem to reinforce this integration, as it focuses on the dispositional rather than behavioural nature of the disorder.

---

3) Category Integration.

Diagrammatic representations such as flow charts were found to be particularly useful for integrating themes.

4) Discussion of emerging themes within a qualitative support group.

*Overview of the research procedure*

The following flow chart illustrates the steps used in grounded theory to move from collection of data to theoretical outcomes (Pidgeon and Henwood, 1996). The specific steps as they occurred in this research are plotted on the right in bold italics.

**Fig. 2.0 : Flow chart of research procedure**

Data Preparation

**Data Collection**

*Narratives*
*Interviews*

**Data storage**

*Transcription*
*Data management*

Initial analysis

**Coding**

*(Re) reading text*
*Placement of text in appropriate folder*
*Index cards*
*Labeling concepts*

Core analysis

**Refine indexing system**

**Memo writing    Category linking**

*Constant comparison*
*Memo writing*
*Category integration*

Outcomes

**Key concepts**
**Definitions**
**Memos**
**Relationships and models**

*Flow diagrams*
*Definitions*
*Memos*

## 2.4. Assessment of qualitative research

The question of how best to assess qualitative research remains a hotly debated and contentious issue. In qualitative research the question of validation of data and emergent theory is not only based on debates of method, but also epistemology. For example, Leininger (1994) believes that it is imperative to use qualitative evaluation criteria to assess qualitative methods and that we should not therefore rely upon the use of quantitative criteria such as reliability and validity to justify findings. A number of qualitative writers have developed their own language to distance themselves from positivist paradigms (Creswell, 1994).

The following represents a brief summary of the ways in which validity, reliability and generalizability have been addressed in qualitative research and the ways in which they were applied in this study.

## 1) Validity

Traditional research defines validity as the extent to which an instrument measures what it is supposed to measure. In qualitative research, validation has been defined as the process by which we evaluate the 'trustworthiness' of reported observations, interpretations and generalisations (Mischler, 1990).

*Internal Coherence*

Validity can be usefully assessed by questioning whether an account presents a coherent argument. Coherence might be evaluated in terms of the way in which loose ends or

contradictions are managed in the data. Also it seems reasonable to assess validity upon the interpretations the researcher makes through the data and whether these seem reasonable.

*Triangulation*

The results of qualitative research are more likely to be accurate if a number of different methods or sources of information are used. Triangulation of data makes use of a combination of methods to explore the topic of investigation. In this case data were collected through interviews and narratives. Triangulation facilitates a richer and potentially more valid interpretation as it increases our confidence that our findings are not simply the result of some peculiarity of source or method (Banister *et al*, 1994).

*Member or respondent validation*

Some researchers have argued that the researcher's interpretations should be scrutinized by participants in the study or validated by the respondents. This would involve asking participants to evaluate and comment upon the interpretations made by the researcher. However, as Henwood and Pidgeon (1995) highlight, this is a complex issue especially if one accepts the role of discourse, power relations and ideological systems in underpinning the outlooks of both respondents and researchers.

In this study, participants were sent a letter (see appendix 11) which briefly outlined the main results from the data analysis. They were asked for feedback on the findings and this

was prompted by some specific questions about the theory. Five of the 8 participants provided feedback and this is included in appendix 14.

Respondent validation had a dual purpose in this study. Firstly, it provided the researcher with an opportunity to express gratitude to the participants for their time and effort and to provide some feedback on the results for their own interest. Secondly it provided the researcher with a fuller understanding of the emerging theory by including their evaluations into the conceptual development of a theory. It is important to state that this was not an attempt to discover an absolute truth about their experiences.

*Qualitative research group*

A support group for trainee clinical psychologists conducting qualitative research met regularly throughout the duration of the research. The group was used as a forum for providing support, guidance and advice on various aspects of the research. It was also used to enhance and develop emerging theories by discussing each others coding and categorization of concepts. For an example of the issues addressed in this group, refer to the minutes taken in one meeting (appendix 12).

*Reflexivity*

Reflexivity is central to all qualitative methods. It is an attempt to make explicit the process by which the material and analysis are produced (Banister *et al*, 1994). In particular, it acknowledges the central role of the researcher in the construction of knowledge.

Throughout the study a detailed diary was kept which was used to explore the process of the research, the personal and professional impact of the research on myself, decisions and rationales, and anything else which was felt to be influential to the research.

*Presentation of evidence*

Smith (1996) suggests good qualitative research should present enough raw data to allow the reader to interrogate the interpretations made by the researcher. A sample of open coding is provided in appendix 13, and the results in chapter 3 will be illustrated with extracts from both the interviews and narratives.

## 2) Generalizability

There is an emphasis in quantitative research on sampling cases in order to generalize to other populations. In contrast, many qualitative researchers have given generalization a very low priority or see it as essentially irrelevant to their goals (Schofield, cited in Hammersley, 1993). Transferability has emerged as the qualitative alternative to generalizability and refers to an analysis of the domains or contexts (as opposed to populations) for which the findings may be transferable or applicable (Flicke, 1998).

For example, the emerging theory may well be repeated as larger themes within society and culture as they are socially or politically prominent at the moment. Morse (1994) claims that theory contributes to the 'greater body of knowledge' when it is 'recontextualized' into a variety of settings. This is referred to as 'theory based generalization' (Hammersley,

1993). Therefore the findings from this study could possibly be transferred to another similar context and still preserve the meanings and interpretations from this study.

Lincoln and Guba (1985) suggest that researchers use detailed description and they describe accurately and in detail the data in their context so that peers and readers have a clear picture of what goes on.

*Theoretical sampling and negative case analysis*

Sampling in qualitative research is driven by theoretical concerns to ensure that the emerging theory is conceptually rich, dense and contextually grounded (Henwood and Pidgeon, 1992). Whilst obviously being limited by the number of participants willing to participate in the research, an attempt was made to sample individuals who had diverse experiences of treatment (such as the duration and type of treatment received).

Negative case analysis involves exploring cases which do not fit an emerging conceptual system (Henwood and Pidgeon, 1992). This represents part of the constant comparative method integral to the grounded theory method. However, it is also an invaluable device for challenging assumptions and categories and for elaborating or modifying theory where necessary.

## 3) Reliability

Given the characteristics of qualitative research, conventional notions of reliability are frequently deemed inappropriate by qualitative researchers. Replication in qualitative

research has, '...more to do with reinterpreting the findings from a different standpoint or exploring the same issues in different contexts rather than expecting or desiring consistent accounts' (Banister *et al*, 1994, p.143). Dependability has been used as an alternative term for reliability within qualitative research. If a study is dependable, it must be consistent and accurate (Holloway, 1997).

*Independent audit*

Quality recording and documentation is a central basis for assessing dependability or reliability in qualitative research. Clear documentation of the research process allows others to track the progress of the research. Throughout the research a 'paper-trail' was left by use of the reflexive journal which documented early hunches or observations. In addition memos, coding and flow diagrams were all dated and filed in accordance with the sequence of the research.

# RESULTS

## 3.0 Outline of results section

The results section will consist of graphical displays of the emergent theory. Analyses of these displays will be illustrated with selections of data from both the narratives and interviews. All raw data are presented in italic text and questions to the participants are identified by bold italic text. Core categories (i.e. those which emerged in all accounts) are labeled in bold and are underlined. Subcategories are defined as categories which either emerged across the course of the data collection, (i.e. were related to further questions regarding the emergent theory) or categories which were confined to particular accounts.

A number of the categories were 'in vivo' in that they came directly from the language used by participants. Such categories are identified in quotation marks to distinguish these from categories which were produced over the course of the analysis by myself.

A core model is identified and is colour-coded, so that in the following sections the categories can be linked to the process of the core model. The sections are divided in terms of the process of the disorder as this enables one to locate the changing meaning of the categories over time. The sections have been labeled:

- The Core Model

- Setting Conditions and Onset

- Maintenance Phase

- Help Seeking

- Treatment and Drop-Out

- Life After Drop-Out

Clearly, some of these categories are more pertinent in addressing the initial research questions. However, all will be addressed in more detail as they help to make sense of the central issue of drop-out. Where necessary, some sections have been supplemented by other models to gain a clearer and more comprehensive understanding of the peripheral sections.

## 3.1 Summary of research questions and aims

It was the intention of this research to develop an understanding of the meaning of drop-out from services for anorexia nervosa. Parallel to this overall aim, the research proposed to understand the significance and meaning an eating disorder might hold for individuals and the implications that therapy has on changing this meaning.

A social constructionist revision of grounded theory was applied to the research data analysis, with the aim of exploring the ways in which meaning may change over time in accordance with, for example, social contexts.

## 3.2 The core model

### Fig. 3.0 The 'Interactional Model of Control'
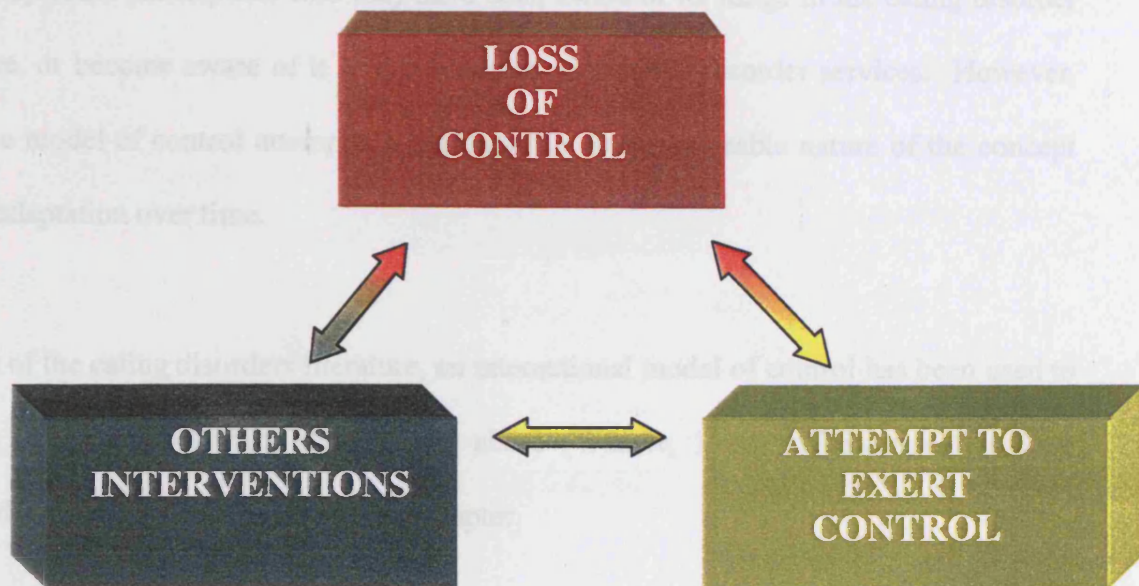


Figure 3.0 illustrates the 'core' model within the experience of anorexia nervosa. This refers to a sequence of events which evolve around a central notion of 'control' and the interactions which affect the individual's sense of control. The boxes have been colour coded and from here on, when a red box is labeled, the experience will be referring to a loss of control. When a yellow box is used, this will refer to the anorectics attempt to re-gain or exert control. The green box refers to the interventions of others (including individuals and systems) which affect the individual's sense of control.

The term control has been frequently used within the eating disorder literature (Bruch, 1973; Slade, 1982; Garfinkel and Garner, 1982; Button, 1985). The model presented here

proposes an interactional model of control, and aims to illustrate the processes operating

which affect an individual's sense of control over time and situations. Control was used

directly by some participants who may have been aware of its usage in the eating disorder

literature, or become aware of it in their contact with eating disorder services. However,

this core model of control attempts to highlight the interchangeable nature of the concept

and its adaptation over time.

Outside of the eating disorders literature, an interactional model of control has been used to

explore self-harm following child sexual abuse (Warner, 1998). This model will be

explored in more detail in the following chapter.

**3.3 Setting Conditions**

**Fig. 3.1 Insidious Onset**
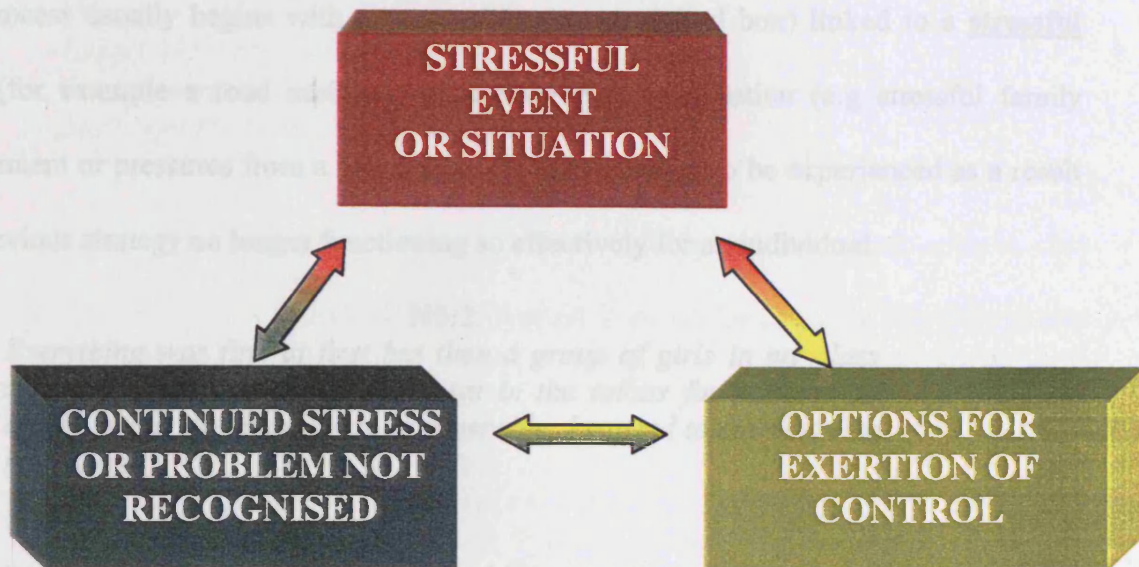


The setting conditions illustrate the pre-requisite conditions for onset of the disorder. The model presented in this section is the combination of data from this study and also from other models which enhance our understanding of this stage of onset. Clearly, it was not the aim of this study to focus on this stage, however, an integration of models is necessary for understanding the complexity of the course of the disorder, and to supplement gaps in this theory by incorporating other models.

For example, it is well recognized that eating disorders are multifactorially determined (Garfinkel and Garner, 1982), and at this stage there may be social (Garner and Garfinkel,

1980), biological (Hsu, 1990; Strober *et al*, 1990), and psychological determinants of the onset of the disorder (Bruch, 1973; Palazzoli, 1978, Button, 1993).

This process usually begins with a sense of **lost control** (red box) linked to a **stressful event** (for example a road accident or bereavement) or situation (e.g stressful family environment or pressures from a ballet school). Stress may also be experienced as a result of a previous strategy no longer functioning so effectively for an individual.

**N5:2**

*Everything was fine at first but then a group of girls in my class started bullying me...One day I sat in the toilets for 4 hours to escape them. Because I was so miserable, I started to cut down on my eating.*

At this stage, there is not necessarily a conscious attempt to exert control, and this may be more a sub-conscious awareness of available **options to re-exert control**. For example, there may be an awareness at some level that there is an emphasis in western societies on the relationship between a thin body and success or achievement. The individual may have limited access to alternative strategies, due to their current environment, or other more idiosyncratic vulnerabilities, such as low self-esteem, personality factors, and cognitive reasoning style. At a more cultural level, there may be an awareness that food is readily available, and therefore food refusal is an available option through which one can demonstrate control to oneself and others.

**N5: 11**

*I felt I could not cope and thought the only control I had was not eating.*

The following interview transcript highlights the combination of psychological factors such as self-esteem, and social pressures in the onset of the disorder.

**I6:57**
*I think I was in my early twenties, and I'd put on a lot of weight. I'd gone up to over nine stone, which I wasn't happy with that, with my height. And it also had to do with my self-esteem, I hadn't got a lot of confidence, I didn't feel I was attractive to other people.*

In this early stage, the **reactions of others** are variable, dependent upon their context. For example there may be **continued stress** or neglect from not recognizing the individual's needs.

**I4:16**
*My mum knew but she never, ever said anything. She never mentioned it to anybody. I mean she used to say eat more, but I kept it away from her because my mum's got an eating problem too. And so she's kind of hiding the fact that she's got a problem.*

Or in contrast, initial weight loss may be **positively reinforced**;

**I3:113**
*I thought I was all right because everybody was doing it at the college and all the teachers were going, 'Oh', you know, 'You look great, you look really great'.*

**N1:12**
*People at work started to nag me about it, but it made me feel pleased that people noticed.*

## Summary: Insidious onset

Participants' descriptions of the onset of their disorder implied that it was insidious, i.e. that the onset was subtle or innocuous, and it is this term which is used to characterize this early stage of the disorder in this research.

## 3.4 Maintenance of the eating disorder

### Fig. 3.2. Conflicts of perception
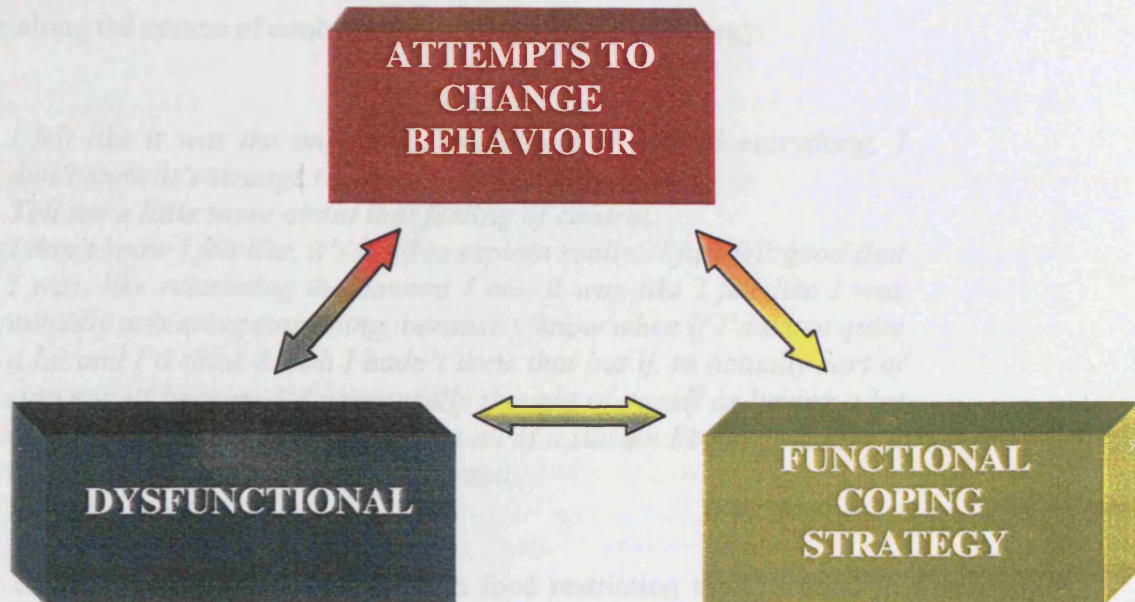


Following the onset of the disorder, the participants described the disorder in terms of a **functional coping strategy**. Its primary function evolved as a means of coping with ongoing **stress** and **exerting control.**

When stress is perceived as beyond one's control, food then becomes a means of achieving a sense of control in conditions of continued stress.

**I5:64**

*...because at first I felt happy with it y'know, I was losing weight and I felt happy that I weren't eating a lot, and I felt like I was in control of everything and it made me feel good. Because if I couldn't control the bullying, I could control something else.*

A factor which appeared to be central in the new coping strategy was mastery or 'achievement' of food restriction. Individuals had to overcome their hunger in order to continue along the course of control becoming an effective strategy.

**I1:352**

*I felt like it was the only way I could sort of control everything, I don't know it's strange really.*
*Tell me a little more about that feeling of control.*
*I don't know I felt like, it's hard to explain really. I just felt good that I was, like restricting the amount I ate, it was like I felt like I was actually achieving something, because y'know when if I'd eaten quite a lot and I'd think I wish I hadn't done that but if, to actually sort of stop myself because I'd never really thought of myself as having a lot of will power before, but it was like all of a sudden I could, y'know. It was quite an achievement you feel really.*

Mastery or achievement of control through food restriction then resulted in a secondary function of **reconsideration of self-identity**. This was particularly potent in cases where there had been confusion about ones self-identity or very low self-esteem prior to the onset of the disorder.

**I7:79**

*An ex-boyfriend of mine made me feel I was nothing, worthless, treated me really bad, and I've never achieved anything in my life. And when I wanted to lose weight and I was getting there, I'd done it, and that feeling was like, I wanted to do that and I've done that. And the buzz that it gives you, is just amazing.*

The new self identity was self-reinforcing, in that to maintain the sense of control and self-will, one had to focus a great deal of energy into maintaining this identity, which resulted in **life becoming focused around food.**

**I1:30**
*It was basically just, at first like, a way of losing weight that I thought
was good and once I had lost it I thought, I didn't see it as a problem.
I just like, my world revolved around that really.*

Such an intense focus on food and the functional nature of the disorder enabled the

individual to screen out any possible negative effects of their eating behaviour. This

appeared to result in the individual becoming **desensitized to the damaging consequences**

of food restriction as this was outweighed by the very positive effects.

**N4:51**
*Nothing about my eating disorder seemed to scare me, even when I
kept fainting and my periods stopped. I was constantly freezing and
couldn't sleep. I couldn't lie in the bath because my bones stuck out.
But all that seemed to matter was weighing less everyday.*

It is unsurprising given the functional nature of the disorder that individuals failed to view

the disorder as problematic, and in effect were in 'denial'.

**N2: 5**
*As many anorexics do, I totally denied any feelings of this
thing that had me totally under control. I was fine, I was not
anorexic and I was not going to become anorexic.*

Denial was further reinforced by the presence of **positive symptoms**, such as excess

energy, and also by initially overcoming negative symptoms, such as hunger. Frequently

the positive symptoms were likened to a drug induced high, and subsequently many linked

the course of the disorder to an addictive process. In order to maintain the positive effects

of food restriction, such as the positive 'buzz' experienced with intense control, individuals

had to constantly **re-set the boundaries** around food intake in order to avoid the coping

strategy losing its potency.

**I4:166**

*It's just like any other addiction, gambling or whatever, you just, y'know when you get a buzz from something, and you lose a bit of weight and you get a buzz, and then lose the same amount but you don't get as much of a buzz, you think well I haven't lost enough, so you lose a bit more and it's just, a vicious circle and you can't stop it, and you're mind gets completely messed up, and I didn't know when I was hungry, when I was thirsty...*

**N4:40**

*I just seemed to get some kind of buzz and was constantly hyperactive.*

Occasionally the **loss of effectiveness** of the coping strategy, resulted in the onset of bulimia nervosa, as individuals had to find alternative strategies to maintain a coping strategy which was invested in the control of food. Bulimia tended to be associated with life spiraling further out of the individual's control.

**I1:248**

*I just started bingeing more and throwing up and that became a big problem whereas I never used to do that before. I never did that and em, that made me feel worse than I did before. I felt like out of control whereas before I felt in control.*

**'Setting and re-setting targets'** around food, enabled participants to test out the limits of their new coping strategy. The following transcript illustrates how achievement through setting targets reinforced the eating disorder.

**I4:330**

*And it was a real exhilarating feeling to know that I thought 'Oh brilliant I haven't eaten for a week, that's fantastic', it was such a big deal to me and I used to set little targets for myself, like I won't eat from now until now, and if I can do that then I'll buy myself a new top. And I used to set goals for myself to convince myself that I didn't want to eat, and that would be my reward for not eating.*

Clearly, there is a stage in the disorder when considerable weight loss becomes apparent to others. Where once weight loss may have been reinforced, the individual has crossed the fine line between an aesthetically thin ideal, and entered into the territory of the 'eating disordered'. This evokes a **reaction** in which it is made clear to the individual, that the weight loss is '**problematic' or dysfunctional**.

### I5:61
*I thought I didn't have a problem, it just seemed like everyone else thought I had a problem, but not me.*

However whilst the primary response to excessive weight loss may be **pathologizing**, this may be tempered paradoxically by society's general valuing of thinness.

### I5:296
*Did you have any feelings about how society in general views people with anorexia?*
*Well I think they think I'm really strange. They don't really understand what it's like. Sort of when I'm out with my mum or whatever, I could feel people looking at me, and I thought they must think I'm really fat. But when I told my mum that, she said they're probably thinking you're really thin. So your mind doesn't think what other people think. It thinks something totally different. I, I, I think there's a lot of pressure on people to think they need to be thin. Like, in magazines and stuff.*

Alternatively there may be a **minimizing** reaction;

### I4:141
*And people don't take it seriously...and it's, people say, don't be stupid just eat.*

Participants felt that in general there was a **misconception of the disorder**, in which society attributed the disorder to a strict diet which was easily reversible.

**I7: 104**
*I don't think unless you've been there, you don't realise how bad it is.*
*I mean people think, oh anorexic she don't eat so she's underweight.*
*It's not. You know when you've got over anorexia when it's gone*
*from here (points to head).*

This reaction and judgment of the problem re-evokes the feelings of being out of control

linked to low self-esteem and identity in the setting conditions. Therefore a third function

of the disorder developed which was linked to a sense of control over ones own and others

'**punishments**'. In some circumstances the eating disorder moderated overwhelming

feelings of guilt, blame and anger;

**I4:219**
*I guess I was kind of punishing myself for the fact that everything was*
*so wrong in my life...and it wasn't my fault, but I felt like I needed to*
*be punished so I did it myself.*

It was also effective in the subtle punishment of significant others;

**I6:112**
*It was a way of getting back at people and a way of controlling them at*
*the same time...so I thought the more weight I lose, the more I'd get*
*back at her (refers to mother).*

The observable nature of anorexia nervosa as a 'disorder' and the spiralling effect of re-

setting more stringent targets evokes a reaction in others which is primarily to save or

**rescue** the individual. The most obvious way to do this is by addressing the most tangible

aspect of the disorder which is the weight loss. Therefore attempts are made to take

control of the individual's dietary intake by use of such tactics as force-feeding and threats.

Such tactics serve to increase the individual's sense of feeling out of control.

**I4:166**
*My mum used to try and force feed me and say, 'You're not leaving the table until you've eaten it'. She used to try and force food into my mouth and I used to be like, that's not the right approach.*

The eating disorder as a coping strategy is still required at this stage as the issues regarding onset are rarely dealt with, stress continues or the coping strategy generalises. However there is also now a need to cope with the tension created by others reactions to the eating disorder which further reinforced the eating disorder as a coping strategy.

A response to this tension, is to alleviate others anxieties by openly 'admitting' that eating has become problematic, whilst internally holding onto the belief the behaviour remains functional. Therefore there exists a contrast in the individual's **public 'admission' and private non-'acceptance'** of the disorder.

**N2: 15**
*After around two and a half years, I finally admitted to others that I was suffering from anorexia, although I could never convince myself.*

**I3:294**
*I said to my mum well, yeah, I think I've got a problem, but I knew in the back of my mind that I had got a problem, but I admitted to my mum, but even though I hadn't admitted it to myself.*

Another strategy is an attempt to **'conceal'** the disorder (from others and oneself) or **'isolate'** oneself from the attention of others.

**N4:4**
*I got away with not eating for a long time as I became vegetarian and convinced myself that I had allergies to wheat etc. This way I avoided eating family meals.*

**I7: 165**
*And nagging at you, (refers to mother) what have you eaten? Are you
going to have this? Was that all you've had today? To me it just
drove me mad, and made me want to stay away.*

## Summary: Conflicts of perception

This stage appears to be crucial in understanding both the experience of the disorder and more importantly the interaction between self and others perceptions of it. The resultant effect is a conflict of perception regarding anorexia nervosa, creating a 'them' and 'us' situation. This distancing of opinions appears to have a detrimental effect in creating a 'reaction' to the disorder, as opposed to an 'interaction' with the individual. What then ensues is a continued battle between the individual's and others perception of the disorder, others' attempts to change the behaviour and the individual's strategies to hold onto the coping strategy.

**3.5 Help seeking**

**Fig. 3.3. Losing control**
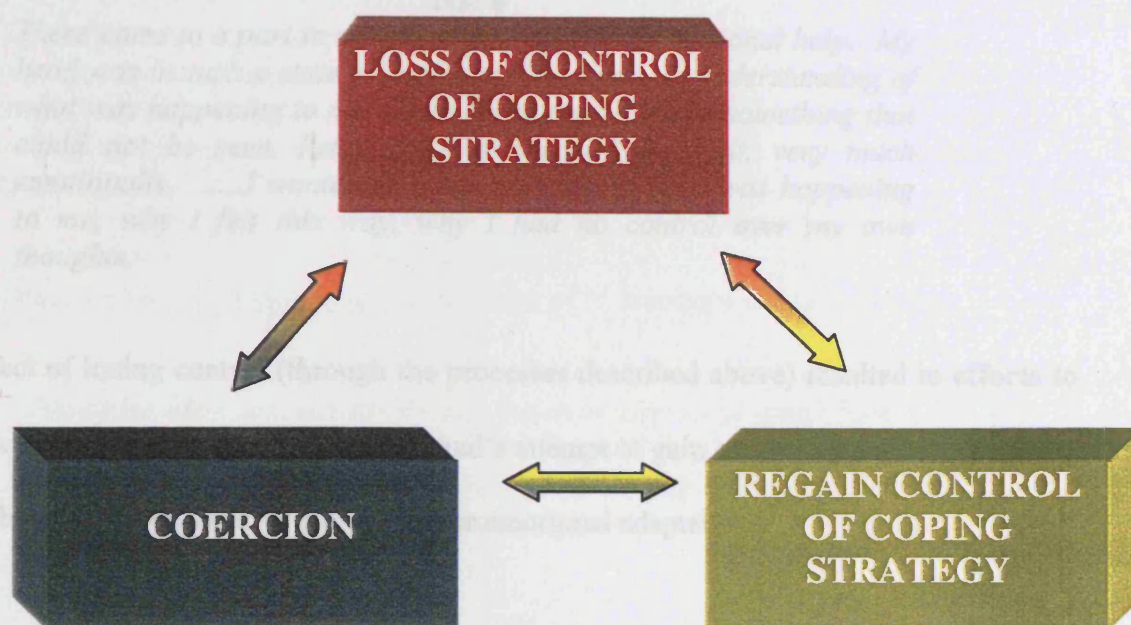


The previous section demonstrated food as central to mastery of control and also the situations, contexts, interactions which maintain the eating disorder as a coping strategy. In particular, it emphasized the process of others' use of extreme methods to exert control over the anorectic and attempts to change their behaviour, which is followed by the individual's use of more extreme methods to regain control.

This process seems to compromise the functioning of the eating disorder and the individual experiences a **loss of control of the coping strategy**. As the following narrative highlights, participants felt that they were losing their grasp on control, so that the eating

disorder was now controlling them, rather than functioning as a method to maintain control.

## N2: 8

*There came to a part in my life when I needed professional help. My head was in such a state of confusion and I had no understanding of what was happening to me. I was being controlled by something that could not be seen, heard or even touched, just felt, very much emotionally. ......I wanted to know more about what was happening to me, why I felt this way, why I had no control over my own thoughts.*

The effect of losing control (through the processes described above) resulted in **efforts to regain control**. This refers to the individual's attempt to gain control by actively changing their behaviour, as opposed to a cognitive or emotional adaptation.

This behaviour change again varies depending upon the social context. In some circumstances the individual became increasingly focused upon starvation and ways to maintain the eating disorder as a coping strategy. For example, the following excerpt illustrates how it may be possible to escalate starvation without heightened reaction from others;

## I2:977

*Also it had to be remembered that it was much easier for me to do it because once [my daughter] had gone to bed I'm on my own, and whether or not I chose to be sick, or whatever. I didn't actually have anybody to hide it from apart from [my daughter].*

Also at this stage, participants may have attempted to overcome the problem themselves by

trying to gain weight;

**I4:243**
*So many times I started getting myself better, so by the time I'd gone to the doctors here, I'd put on about a stone and a half on and I'd managed to do that myself, but I just couldn't get past that first bit. I started putting weight on and somebody would say one thing and it would all go to pot again.*

In other circumstances **seeking help** was a means of re-gaining a sense of control.

**N3:11**
*My eating disorder continued and I began to binge and vomit a lot more as well as taking laxatives. During my A'levels I started to feel that I would like some help, but part of me still wanted to stay the way I was. It wasn't until university that I felt I couldn't cope anymore.*

Where participants had acknowledged a need for help, the aims of seeking help appeared to

centre around gaining understanding of the eating disorder.

**N2:13**
*I wanted to know more about what was happening to me, why I felt this way, why I had no control over my own thoughts.*

Participants were, however, **coerced** to varying degrees into seeking help for their eating

disorder. Coercion, again, seemed to challenge the notion of the disorder as functional.

**I3:112**
*I was coming along for my mum's sake, but I hadn't really admitted to myself that there was a problem.*

**I1:65**
*What was the reaction of your mum to going along to the service
and your family. What did they think?
Well obviously they wanted me to go and when I wasn't going back,
she was like "You are" and I just said "I'm not" and I just didn't go.
I used to get really wound up and I used think (.) I didn't want to
upset them, but, they dragged me there anyway.*

Clearly, this coercion into accepting help for their eating disorder, created a sense of

**ambivalence about change**, as the following excerpt highlights;

**N4:28**
*Half of me was crying out for people to help me, the other half of me
wanted people to leave me alone. I think I agreed to have treatment
at that point mainly for my family. I felt terribly guilty that my mum
in particular was so worried about me.*

Having sought help, the individual was faced with integrating a new **label** for their coping

strategy. The behaviour which had been so functional, now had a specific diagnostic label,

one which required the help of professionals to overcome. This label and conception of the

disorder was an obvious contrast to the individual's perception of the 'disorder'.

**I2:396**
*I never really thought, and I still don't think I had a problem. I'm not
the sort of person to turn around and say "I'm **** and I'm an
anorexic" y'know, but I never perceived it as a problem, it just felt
like a healthy way of eating that I knew I had control over.*

Frequently, individuals had heard of anorexia nervosa, and there appeared to be vivid

visual images associated with the label. Overwhelmingly, participants felt that they did

'**not fit this image**', which further increased their sense of ambivalence and uncertainty

about seeking help.

**I7:41**

*And I hate the word. I think everybody would hate the word. When people used to say to me, 'You're anorexic', 'I'm not, I'm not'. Because of the fact because an anorexic is really thin and you're not really thin.*

**I6:301**

***What did you think when you first got this diagnosis?***
*I felt guilty and ashamed, I think was the first reaction that I'd come to this state. And I felt I'd failed. You know how could I have possibly got myself into this mess.*

In addition to the label of anorexia nervosa, participants had to contend with a mental health diagnosis which again located the problem at a very individualized level, detached from the context of its onset and the functions which were maintaining it. In the following excerpt, the participant appeared to be expressing concern about the pathologizing label of the service.

**I3:72**

*It wasn't the fact that it was eating disorder, because I think I knew at the back of my mind that I did have a problem, it was just admitting, but it was the fact that I was coming here, into the hospital, because it was the Mental Health Unit and I thought there was something wrong with me, and that's the fact, that I refused to be, because the fact that it was a Mental Health Hospital and I obviously thought they were saying that there was something wrong with me in the head.*

Seeking help for the eating disorder forced the individual to consider life without anorexia nervosa as a functional coping strategy and the effects that treatment would have on surrendering control. This stage of **contemplating the meaning of treatment** appears to resemble yet another stage in which issues of control are deliberated.

**N2:31**

*This was a big step for me to take; did I really want to get better? Do I really want to start putting on weight? The fear of coming and getting help was overpowering, but I knew I could not go on like this anymore.*

**I1:364**

*I suppose I felt quite nervous about changing it and I thought, I don't know whether I want to. I don't know, feel out of control.*

Uncertainties about change at this stage appear to resemble the **acceptance versus admission** category in the maintenance stage. For example, the decision to accept a referral for professional help, attendance at the unit, and admission of an eating disorder, may all be seen by the professional as acceptance of the disorder as problematic or dysfunctional. However, participants had seldom accepted the disorder as wholly 'problematic'.

## Summary: Losing control

The process of seeking help appears to be characterized by decisions about surrendering some control to others. The impetus to seek help is initially prompted by the concerns of others which has implications for the individual's motivation to change in the following section. In addition, at this stage, the individual is faced with a new understanding of their eating behaviour in the form of a psychiatric diagnosis. The participants were reticent about accepting this diagnosis as it was sometimes viewed as pathologizing their coping strategy or because it did not closely relate with their experience of the disorder. In addition, low self-esteem and issues regarding identity which are frequently linked to the

setting conditions of the disorder, may have been exacerbated due to the pathologizing

label of anorexia nervosa.

## 3.6 Treatment

**Fig. 3.4. Challenges of treatment**
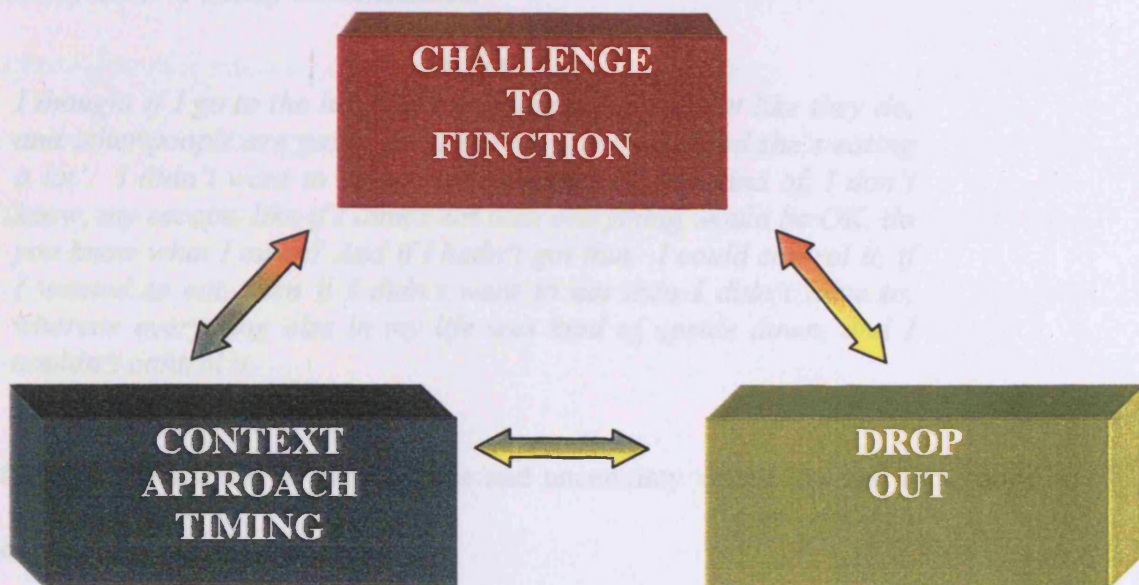
The previous section outlined the conditions, processes and interactions leading up to treatment for anorexia nervosa. In particular it was apparent that motivation was frequently low given that individuals had often been coerced into accepting a referral for treatment. In addition, the label of anorexia nervosa operated in such a way that it distanced the individual's and the service's perceptions of anorexia nervosa.

Having accepted a referral for treatment there appeared to be specific consequences for the individual, particularly regarding the perception of the disorder and the belief that treatment would change this perception.

Clearly, the **consequences of treatment** were varied and dependent upon the individual's context. For participant 3 (a dancer), there were pragmatic decisions regarding her career. For participant 4, it was associated with fitting into normality, when this was difficult given her physically abusive family circumstances.

### I4:213

*I thought if I go to the hospital I'm going to have to eat like they do, and other people are going to look at me and think 'God she's eating a lot'. I didn't want to be normal because that was kind of, I don't know, my escape, like if I didn't eat then everything would be OK, do you know what I mean? And if I hadn't got that. I could control it, if I wanted to eat, then if I didn't want to eat then I didn't have to, whereas everything else in my life was kind of upside down, and I couldn't control it*

Again, this created a sense of ambivalence and uncertainty which lowered motivation to engage or continue treatment.

### N4: 80

*My mum promised me that this time I would get better and she persuaded me to go for my appointment in ****. She and [my husband] were behind me 100%. I still however wasn't fully committed to getting better. Maybe 60% of me did, but I still couldn't see any future without my eating disorder.*

Within treatment, interventions of others are categorized into the effects of the '**approach**', '**context**' and '**timing**'.

In terms of the treatment '**approach**', participants felt that there was a **lack of negotiation** and that they were quickly made to feel passive which increased their sense of lost control.

**I5: 634**
*I felt I didn't have any control with both [inpatient services], because you couldn't go out for a walk if you wanted to, and it's almost like you have to do that, you have to go by the rules.*

Participants tended to experience treatment as primarily '<u>focusing on the symptoms</u>' of the disorder. For example all participants were given a goal/target weight in the services they accessed. This was generally viewed negatively as again, they felt there was inflexibility in negotiating the individual's targets. Frequently the target weight was discussed in the early stages of assessment or treatment when many had not fully accepted anorexia nervosa as a problem.

**I2:353**
*[The therapist] told me how much I had to put on, I just said I'm not coming again (laugh).*

Again, 'admission' of the problem may have encouraged professionals to pursue targets and weights at this early stage, before checking out with the patient whether or not there was an acceptance of the disorder as a problem.

**I3:301**
*I hadn't really admitted it to myself, but I admitted it to everybody else, I'd admitted it to the doctors which probably made it, it's probably why they were like they were. They were straight to the point and tried to help me in a way. They were more like say you've admitted the problem, this is what we're going to do sort of thing.*

If imposed goals were disputed by the patient she then perceived herself to be 'resistant'.

**I1:76**
*I didn't want to put on weight and that was what they were focusing everything on. And I didn't want to do that so, It was like they telling me I had to do it and I was thinking I don't want to. And they didn't seem to understand that I didn't want to.*

Participants experienced a continued 'focus on the symptom' through the provision of food diaries, either as an exclusive treatment method, or as part of an assessment. The focus on the symptoms, through such an approach, again located the professionals concern with the individual's behaviour. Clearly, this was a repeat of the initial reactions to the disorder in which others reacted to the most obvious and distressing aspect of the disorder for them; the weight loss.

**I6:135**

*I don't think he was sensitive enough to see what I really needed. He just kept focusing on the eating, he kept focusing on weighing me and keeping this diary. Week after week I had to keep this diary and I had to weigh myself.*

Often viewing consumption in black and white through the use of food diaries compounded the problem, and for some led to re-setting more stringent targets.

**N4:93**

*I was weighed once a week and she asked me to keep a food diary. This however, made me much more conscious about what I ate and seemed to compound the problem.*

The focus on the symptoms appeared to enable the individual to continue their effective strategy of 'focusing life around food' as a means of coping with stress and other issues. To some degree, it may have therefore reinforced the eating disorder.

*13:196*
*I was really confused. The fact that they were sending me home with this is what you're going to have for your breakfast, this is what you're going to have for your lunch, this is what you going to have for your tea. I was confused with the fact that they'd given me that and gone sent me home with that and say right go home and do that, because I knew I wouldn't. I mean, it's more trying to tackle the fact that why wouldn't I go and do it.*

In particular instances, the treatment was perceived as aversive, and again, re-enacted the reaction of others to the onset of the disorder.

**N5:25**
*We were forced to eat or we would have to go on a drip.*

**I1:244**
*[The therapist] was very threatening and really trying to scare me and I don't know, I suppose he came in with the attitude that if he tried to shock me it would snap me out of it but it had the opposite effect really.*

The treatment **'context'** evoked comparisons between the participants and both eating disorder patients and psychiatric patients. Each appeared to result in a sense of not fitting in, an alienation from reality and unworthiness for therapy.

**N2:35**
*When I first arrived at the hospital I was so ashamed, I was far too fat to be at a clinic like this, I thought I would be laughed at.*

The context of the hospital was far removed from the context of where their problems were located e.g. within the social situations of the family, school, work etc. It also seemed to increase their sense of passivity as it was aligned to a 'sick role'.

**I2:675**

*I think that had the actual environment itself not been attached to that particular part of the building, had it been a bit more homely and less like an office and less like a hospital, I think that kind of thing may be would have influenced me a bit, and I would have felt a bit less like a patient, but I still didn't think I was ill, I still don't think I was ill, but y'know people around me were saying 'This isn't normal you're ill' and I didn't feel ill.*

The label of the 'Mental Health Unit' was also alienating as it located the problem once again with the individual's mental health. Many felt that they were indeed 'mad' and out of control in the view of others. This further increased a sense of distance between the eating disorder as functional and dysfunctional – widening the gap between themselves and others.

**I3:87**

*I think that's why I stopped coming as well, because I thought there was something wrong with me in my mind, and that was hard to accept.*

It appeared that the **'timing'** of treatment was occasionally ill-considered, given the individual's circumstances (such as context, stage of acceptance or denial, implications of change).

**N4:107**

*It was the only thing I felt I could control and still wasn't ready to give it up...it wasn't the right time for me, but I feel annoyed as I might never get the chance again.*

All such issues are a challenge to the individual's perception of the problem, and may again create a conflict between themselves and others. The approach, context and timing of the treatment all appear to recreate the conditions of lost control.

**I5:406**
*I don't feel I had any control over anything.*
*And how did that affect the problem?*
*Well it didn't help because they just put weight on me, and they weren't*
*solving anything. They just thought, 'Oh once she's put weight on she'll*
*be fine', and that weren't the case.*

When the functional nature of the disorder has been challenged in such ways over time, the

individual seems to have two options when faced with similar issues in treatment;

1) to surrender control to others in the hope that the professionals will 'solve' the problem,

2) drop out of the service whilst holding onto the belief that the eating disorder remains a

   functional coping strategy.

In this way, drop-out appears to be linked to a process of re-gaining control over the

perception of the disorder and re-gaining control lost within the treatment context.

In the following transcript excerpt, the participant explains that treatment seemed to focus

on her eating to the extent that she felt neglected at a personal level. For her, dropping out

was linked to gaining control over her personal identity.

**I2:410**
*It was like being under a microscope and it was like, my eating was so*
*much of a focal point.*

**I2:434**
*What I found I've done now, now that I've actually finished the counselling and refused the anorexic clinic and everything else is that I've completely shut down as far as being open about anything, because I want to be able to step back again, and..*
**What's stepping back about do you think?**
*Because I don't want them to be able to know me inside out anymore. I want there to be some respect again.*

Interestingly participant 6 was unaware that her second contact with the service had been viewed as a drop-out. Her G.P. had assumed she required help for her eating problems, as she had been treated for anorexia nervosa twenty years previously. She attributed weight loss to depression which she felt was the root of her problem and drop-out for her was a means of ensuring that she received help for what she understood to be most central to her problems. In this instance drop-out was linked to an attempt to take control of her perception of the disorder.

**I6:236**
*I said I don't really want to sort out my eating problem, that was not the problem, I'd rather talk to a counsellor and sort out my depression.*

## Summary: Challenges of treatment

The experience of treatment (particularly with regard to the approach, context and timing) in combination with the individual's perception of the disorder, appear to re-create the setting conditions of lost control and present very real 'challenges' to the individual. Rather than working with the individual's stage of understanding and beliefs regarding the disorder, treatment immediately challenges this functional coping strategy in sometimes very obvious ways (such as the setting a goal weight and food diaries) and sometimes by

utilising more subtle strategies (such as the pathologizing label of the 'mental health' service and its 'clinical' context).

This section has illustrated that when presented with such challenges, the individual has the option of risking continued loss of control (often without being equipped with alternative coping mechanisms) or drop-out. If the decision is made to drop-out the individual may take control over her perception/understanding of the disorder or re-gain control lost within the context of treatment.

### 3.8. Life after drop-out

**Fig. 3.5. Partial recovery**
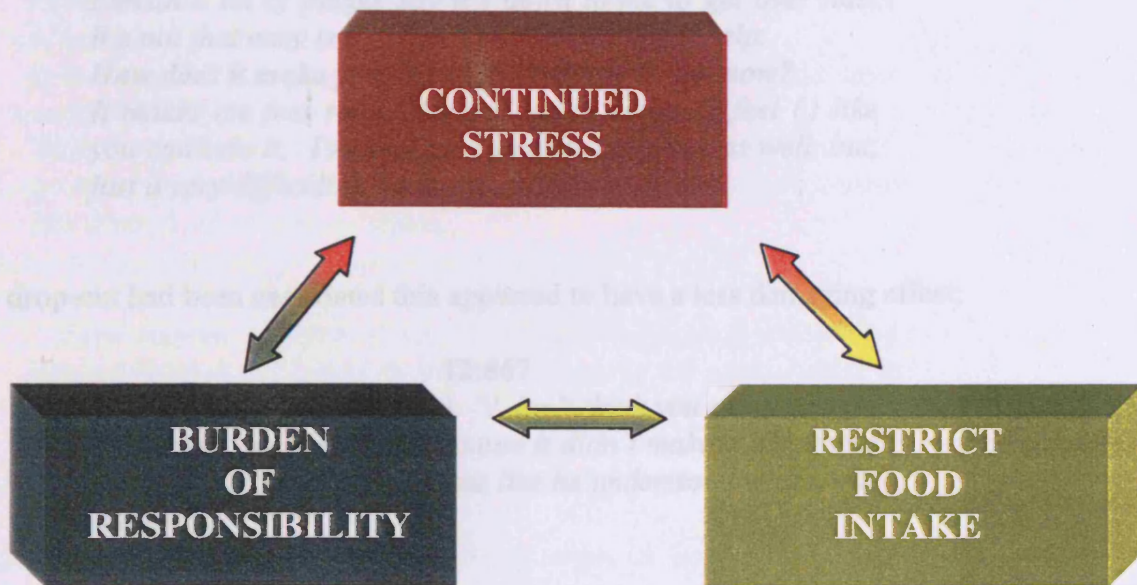


Although initially participants seemed to experience a sense of relief after they had dropped

out, in the long-term individuals seemed to become further distanced and isolated from others.

As the following quote suggests, participants continued to use strategies such as concealment

which enabled them to avoid public scrutiny and further loss of control.

**N1:57**

*I wear bigger clothes at work to hide my weight loss, to avoid nagging.
I don't go out for lunch or out with my friends much so they can't tell me
about my weight.*

Participants felt they had failed a 'specialist' service and therefore blame and responsibility

tended to be internalized.    Overwhelmingly participants referred to a **burden of**

**responsibility** for their eating disorder. The term 'burden' was applied as responsibility

did not appear to be viewed as an empowering element.

> **I5:808**
>
> *I mean a lot of people say it's down to me to get over this.*
> *It's not that easy is it? I don't know what might help.*
> ***How does it make you feel that it's down to you now?***
> *It makes me feel really isolated, quite alone. I feel (.) like*
> *you can't do it. I mean I said you need support as well, but,*
> *just a very difficult thing to do.*

Where drop-out had been negotiated this appeared to have a less damaging effect;

> **I2:867**
>
> *He said (refers to therapist), "I don't think you are ready for*
> *treatment", which is fine because it didn't make it like it was*
> *all my fault then really, it was like he understood which was*
> *quite nice.*

Participants spoke of recovery in terms of it being **partial** i.e. that their eating would

remain disordered to varying degrees.

> **I2:799**
>
> *..in some senses I've probably still got it, but (.) you can*
> *learn to live with it, you just accommodate your life to live*
> *with it, it's not a problem. It's only a problem in other*
> *people's eyes. I mean what is normal eating?*

> **N2:1**
>
> *I am 22 with 2 children, and have suffered with anorexia*
> *nervosa for three and a half years but have finally*
> *recovered. However, I cannot say fully recovered because I*
> *don't think you ever do.*

The partial nature of recovery seemed to be influenced by;

a) the use of restriction of food as a **transitory coping strategy** under conditions of

continued stress,

**I1:560**

*I'm just thinking about your actual symptoms now and your
eating disorder, has anything got worse, or has anything got
better in terms of the eating problem since you left?*
It's not really got any worse, I don't know. I'm still not right or
anything but, there are days when I have bad days and other days
I have good days y'know.
*Is there anything that happens in your life to make the good days
and the bad days?*
Yeah, I mean yeah definitely. If I have a good day at college and
go out, I do feel good. But as soon as anything bad happens that's
like when it all circulates again.

**I6:463**

*...there may be a future date when I might go back, something
might trigger it off. But I don't think I'd go as far back, I think it
just may be temporary.*

b) the integration of the label as a 'dispositional' characteristic. The processes and

interactions operating throughout the various stages of the eating disorder from onset to

treatment, appear to eventually reinforce the label so that the individual views anorexia

nervosa as an integral part (possibly a friend or foe) of themselves.

**I7:266**

*It is part of me. It was a separate friend, and it is part of me now. It's
there now. I could just if I wanted to just turn to it, and go right back
down.*

**I6:406**

*I think that I've failed if I can't sort my problems out myself then I've
failed, there's something wrong with me.*

Participants' recommendations for improvements in eating disorder services were

consistent with their reported experience of the disorder. For example, a common request

was that professionals should **focus on understanding** as opposed to 'focusing on the

symptoms'.

**I6:483**
*...they've got to recognize that anorexia is part of a symptom, of what's going on in a person's life. Sort out what the real problem is, get to the bottom of it and then sort out the eating disorder.*

Consistent with their confusion over the meaning of treatment, participants requested that therapists **negotiate the individual meaning of recovery.** As the following excerpt highlights, therapists may sometimes assume the goals of therapy which can lead to patients becoming unmotivated to change.

**I2:751**
*Well how much will I actually get from the therapy and did I really want to get on that much with my mum. It wasn't worth one and a half stone (laugh). Whereas if they'd said to me, 'Lets talk about (daughter) and how you're going to be a mother, that would have been worth much more to me.*

Where therapists had begun to focus on 'understanding', it was often tainted by the expectation that weight gain was the ultimate goal.

**I2:1017**
*I do think there's problems about women's bodies and body image and stuff. But anorexia isn't about that, it's about control and it's about deviance...because something else is lacking in your life. I feel sometimes that it's treating the wrong thing, and they should be looking back. They almost hit it by saying well 'We'll look back at this relationship with your mother', but then you've got this thing on the end, whereas if they'd just said to me, 'Lets look back at this a bit longer, and we'll keep weighing you each week, and just see what happens'*

The **dual roles** of the therapist to monitor weight gain and provide a therapeutic environment were not always complementary. The following excerpt suggest that failure to gain weight can generalise to the rest of the therapy session.

**I4:260**

*I was kind of saying, 'Oh yeah I haven't taken any suppressants this week' and I'd think oh I've taken a couple of packets (laugh), but I couldn't tell him the truth because I thought in a way he'd be disappointed in me, and I didn't want to disappoint him because he'd had so much faith in me.*

Participants overwhelmingly felt that **contact with recovered anorectics** would be beneficial if not central to recovery. This may be linked with the pathologizing experience of treatment in locating responsibility for change at an individualized level. Such contact might be perceived as empowering for individuals as they had a common or shared experience and understanding of their problem which was in opposition to the overpowering perception of their family, friends and professionals.

**I7:179**

*Like for an anorexic to recover, I think she needs to speak to somebody that's recovered from anorexia. That is the only way I believe anybody can cope with it. They know what you're feeling, they know what you want, y'know, they know everything that's going off in their minds.*

In addition, the dis-empowering context of the hospital was highlighted for change. It was felt that the hospital environment was far removed from the reality of the context of eating problems.

**I2:1617**

*..just take it out of that context of like a hospital clinical environment, because that's not where you eat is it? It's like so abstract.*

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## Summary of results

This chapter has outlined the various stages of anorexia nervosa and the ways in which interactions and contexts shape the development of the disorder over time. In particular, the maintenance section is viewed as crucial in understanding the response of drop-out in treatment.

It has been argued that within this section, the reaction of others creates a conflict of opinion regarding the function of the disorder which compromises the nature of the eating disorder as a coping strategy.

Within treatment, such conditions and interactions are reinforced and exacerbate the challenges previously created for the anorectic. It is argued that drop-out is a means by which the individual re-asserts control over the perception of the problem as they are unable to integrate others' notions of the disorder as dysfunctional and problematic. In addition the conditions of treatment re-create loss of control so that by dropping out the individual is behaving in such a way that they protect themselves from further loss of control.

## DISCUSSION

## 4.0 Overview of chapter 4

The previous chapter stated the main findings from this research. This chapter will aim to interpret these findings with reference to the research questions and literature outlined in chapter 1. An attempt will be made to explore the significance of new findings and how this relates to current conceptualisations of drop-out. The implication of the findings with regard to theoretical, organisational and clinical developments will be discussed prior to a critical evaluation of the research.

## 4.1 Aims of this study

The main purpose of this research was to explore the meanings attached to the act of dropping out of services for anorexia nervosa. Linked to this overall aim, an attempt was made to elucidate the function and significance of anorexia nervosa for the individual and the implications that treatment might have on this meaning.

A social constructionist approach was adopted as this seemed to be appropriate to the research aims of analysing the ways in which meaning might change over time in relation to specific contexts.

## 4.2 Outline of the main findings

The analysis of this research illuminated the concept of 'control' as central to understanding the process of drop-out from treatment services. The overall model has

been labelled as an 'interactional model of control' as it has been argued that the concept of control is interchangeable depending upon various contexts, interactions and processes, which serve to increase or decrease an individual's sense of control.

*The Core Model*

This core model illustrates the cycle of interactions which occur at various stages of the disorder. There is no set sequence with regard to this process as this varied within each case, hence the use of two-way arrows in the diagram. This model revealed the effects of various interactions and contexts over the course of the disorder which accumulates in the act of dropping-out of treatment services.

In terms of the specific questions highlighted at the outset of this study, it appears that there is no singular meaning attached by all participants to the act of dropping out. Clients dropped out for a vast array of complex and interacting reasons. However, there appeared to be a common 'cumulative' effect of the interactions between 'others' (meaning family, friends, professionals and the wider social system) and the individual sufferer regarding the perception of the disorder as either functional or dysfunctional over time. This subsequently impacted upon the individual's sense of control and gradually eroded the functional nature of eating disorder by recreating the setting conditions of lost control. Within treatment the implicit and explicit tactics reinforce the process underway and restrict the individual's options for recovery.

The second aim of this study was to understand the meaning of the disorder and the implications that treatment has on changing this meaning. What was apparent throughout the analysis was the 'functional' nature of the disorder in the eyes of the sufferer. Primarily, anorexia nervosa functioned as a means of coping with stress. The way in which this coping strategy operated was specific to individuals, but again centred around control of oneself and others.

This research highlighted the ongoing battle between the individual's efforts to maintain the coping strategy and others attempts to change the 'problematic' behaviour. Therefore, it is not just treatment which presents a challenge to the sufferers' meaning of anorexia nervosa, but a whole range of other systems including the family, the community and society in general. The core model reflects a whole range and complexity of processes and interactions which challenge the individual's coping strategy and which accumulate in the act of dropping out of services. Therefore, the meaning of the disorder is integral to understanding the meaning of drop-out.

*The construct of control*

'Control' is a term that is all too familiar to anyone who suffers from anorexia nervosa. Within the research literature the disorder is frequently described as a syndrome of 'pathological control' (Bruch, 1978; Crisp, 1980; Slade, 1982; Lawrence, 1984; Button, 1985; Lask and Bryant-Waugh, 1993). However, the ways in which it has been applied in the literature suggest that it probably engenders multiple meanings.

Some researchers have located the issue of control in specific contexts, such as the family (Palazzoli, 1974; Bruch, 1978), or wider socio-cultural or political contexts such as the feminist research (Orbach, 1986; Lawrence, 1984); whilst others have confined the issue of control to an intra-personal struggle linked to personality, cognitive or emotional predispositions (Bruch, 1973; Garner and Bemis, 1982).

More recently, researchers have been assessing the impact of various treatment approaches on the issue of control. There appears to have been a growing awareness that if control is pertinent to the onset and maintenance of anorexia nervosa, then treatment itself may pose great risks to the individual's attempt to maintain a sense of control (Bruch, 1985; Sallas, 1985; Goldner, 1989; MacSween, 1993; Jarman et al, 1997).

However, if an ambiguity about the meaning of the concept of control exists, then researchers may be dealing with very different aspects of control when dispensing advice to clinicians on how to overcome this issue in treatment. Furthermore, in practice there appears to be a contrast in the way in which practitioners deal with issues of control. For example, some services advocate the need for the patient to have complete control over treatment (Sanger and Cassino, 1984), whilst in others the service philosophy is for treatment to resolve the patient's dilemma by taking control for them (such as the inpatient service in this research).

Research has also tended to focus on the implications of control within the therapeutic relationship and have generally neglected the individual's wider context such as society's

reactions to the disorder. Hopefully, what this research can contribute is an enhanced understanding of the ways in which issues of control operate at various stages of the disorder.

*The elements of control*

Given that findings from this study may have the potential to define more clearly the elements of the anorectic's struggle with control, it is useful to now distinguish what some of the central aspects are and how they operate. These do not operate independently and therefore there is an obvious overlap between them.

a) Coping Method

In certain circumstances (e.g. unavailability of other means of achieving a sense of control) anorexia nervosa is a method by which an individual can take control of life and in the process provide a mechanism for coping with stressful circumstances.

Surrounded by stress and confusion, it is a means by which the individual can narrow the influences around them to focus on one specific element through which they can gain a sense of control.

b) Identity and Self-image

In the process of focusing life around food, starvation may become an activity by which the individual can re-define themselves. Given that self-esteem and identity issues are

implicated in the onset of the disorder, success at starvation is a means of defining oneself in terms of achievement, rather than 'weakness' or 'badness'.

Again, this overlaps with Orbach (1985) who writes, 'Whereas we see [the anorectic] wasting away and disappearing, she feels herself to be strong for she is in the process of creating, of making out of herself, a new person, one whom she can admire, from whom she can gain a little self-esteem' (p.132).

c)  Perception of the disorder

For the anorectic, starvation is a way of coping when times are stressful. Depending on the reactions of others, this coping strategy may be generalised. But the weight loss is viewed by other people as 'problematic' and something which requires an immediate remedy. Whilst the individual may feel empowered by the effects of the disorder, to those around her she is perceived as ill and weak.

This battle of perceptions links with Orbach's (1985) notion that for the individual, anorexia nervosa, is not the problem, but the solution. As she states, 'Whilst everyone can see her anorexia, no one can see the person behind the anorexia' (p. 132).

*Links between the 'interactional model of control' and other models*

The findings from this study do not necessarily exclude other ways of understanding the experience of treatment for anorexia nervosa. There may well be overlaps with other clinical disorders in which the symptoms of the disorder evoke a similar cycle of control.

Warner (1998) has developed a similar model to explain the interactions in the treatment of individuals who have been sexually abused. Aggression and self-harm may be equated to starvation as a means of gaining control and coping with trauma in this instance. However, because this behaviour is so excessive and extraordinary (particularly for women) this then becomes the main focus of concern. Understanding the reasons behind the actions are then neglected in favour of controlling and containing the behaviour and therefore 'The chains of meaning are broken' (p.1). In psychiatric and special hospitals women lose more control and are confronted with the same issues which may have contributed to their distress in the first instance (Reavey and Warner, 1998).

A number of the core categories from this study overlap with existing models in the eating disorder literature. For example Slade (1982) viewed anorexia nervosa as an attempted adaptive strategy which had 'functional value' to the individual. In this way, anorexia nervosa is viewed as a secondary adaptation to more general psychological problems. This equates to the 'functional coping strategy' labelled in this study. Slade (1982) utilised a functional analysis model which viewed behaviour as a function of antecedent events (such as setting conditions) and consequences (such as reinforcement).

Slade (1982) assumed, however, that the functional nature of the disorder is lost after the initial setting conditions, and that the individual is simply responding to powerful reinforcing consequences. What has been highlighted in the present model presented in this research, is the ongoing functional nature of starvation as a coping strategy throughout various stages of the disorder, particularly as a means of coping with reactions to the

symptoms of anorexia nervosa. Furthermore, Slade (1982) neglected the construction that the individual and wider society placed on the disorder and the effect of this on the perception and meaning of anorexia nervosa.

In a qualitative study of the meaning of anorexia nervosa to long-term sufferers Button *et al* (1998) argued that anorexia nervosa may represent a way of coping as the individual is able to focus their life around the control gained from food restriction, when faced with wider difficulties such as low self-esteem and problems in interpersonal relationships. The present research highlighted the long-term vulnerabilities of patients in their struggle to function without the use of extreme weight control, 'Whatever the initial pathway to the onset and establishment of the disorder, the person develops a way of life which may become meaningful and less threatening than the alternatives of eating normally or leading a normal life' (p.3). There are clear overlaps here with the 'partial recovery' noted in this study in which continued food restriction functioned as both a coping strategy and to consolidate one's identity.

The findings from this study resonate with much of the current feminist literature on eating disorders. For example, Sesan (1984) described how hospitalization for treatment engenders frightening images of dis-empowerment for the client. Such settings may perpetuate a pattern of oppression by rigidly controlling women's behaviours and actions and inadvertently silencing them once again. In attempting to control the symptoms of eating disorders, services may well prevent women from expressing themselves the only way they know how.

Carr (1989) described similar effects when professionals work with families in which a child has been sexually abused. The responses of professionals to trauma associated with child abuse are labelled as countertransference reactions. He outlined a familiar triangle in which the victim is characterised by helplessness, the persecutor role by aggressiveness, and the rescuer role by helpfulness. Such countertransferences, according to Carr (1989), can interfere with the capacity for collective balanced decision-making about child protection.

Anderson and Stewart (1983) explained drop-out from a range of psychiatric services as;

1)  opposition to loss of self-determination,

2)  fear and vulnerability to a stranger's perceived reality and value judgement,

3)  fear and stigmatization of mental illness.

There are similarities here, with many of the findings from the present study which were referred to as a battle of control regarding the perception of the disorder. In addition, Marsh and Stanley (1995) attributed drop-out from eating disorder services to a difference of perception between the socially imposed negative qualities and the generally positive construing of the disorder by the anorectics.

Theoretically, such commonalties in these explanations of drop-out might be construed by strategic therapists, such as Erikson (1980) as the client's efforts to maintain a consistent interpersonal stance. Van Denburg and Van Denburg (1992) have attributed such

similarities to conflicts over dependency and the individual's efforts to maintain a sense of control. However, in the present study, the battle of control referred to more than dependency and was linked to wider interactions than interpersonal conflicts.

Research investigating anorectic patient's views on their treatment seems to be consistent with the findings from this research. Patients seem to be very concerned that their treatment is focused only on a symptomatic level, but in contrast patients need to be able to talk about their illness with someone who understands it from their own viewpoint. Two studies suggest that opportunities to discuss the meaning of anorexia nervosa are important in recovery (Hsu *et al*, 1992; Newton *et al*, 1993).

*Unexpected findings*

The primary focus of this study, 'drop-out' has become secondary to an exploration of the meaning of anorexia and the subsequent struggle for control in treatment. This focus became apparent whilst conducting the interviews in which participants were intent upon discussing their 'experience' of anorexia nervosa.

Timing was a factor which was taken into consideration in the analysis of the meaning of drop-out. However, this did not appear to be a pertinent factor as the meaning of drop-out was influenced by much more complex events and interactions which were specific to the individual. However, a larger scale study will be needed if this issue is to be addressed more appropriately.

The concept of control is not a novel one within the eating disorders literature. However, it has tended to be used as a static concept often utilised with reference to the very early stages of onset, and occasionally maintenance. It was apparent from the present study that the concept was ever-changing, dependent upon interactions within a wider social structure, and over the duration of the disorder.

## 4.3 Implications of the findings

### a) Theoretical

Anorexia nervosa has been conceptualised in many different ways by the major theoretical paradigms. There are, however, some important similarities which may help us to understand why no one method has had overwhelming success. Many conceptualisations seem to be based upon the premise that anorexia nervosa represents a pathology, and situate change at an individual level. What seems to be absent is an integration of these conceptualisations with a social analysis of eating and weight in our culture.

The results of the present investigation do not lend support to theoretical conceptualisations of drop-out which locate the cause at an individual level, such as purely psychodynamic or cognitive approaches. In focusing upon change at this level, the wider interactions affecting the individual's sense control are neglected.

Cognitive approaches imply that people will change given the right information. However, services may be providing inappropriate information at present, such as focusing on food

and weight. Psychodynamic approaches may address how social mechanisms become internalised as coping strategies, but some may be in danger of focusing on fantasized rather than real relationships.

Eclectic approaches such as cognitive analytic therapy (CAT) have been applied to the treatment for eating disorders. Denman (1995) suggests that both cognitive-behavioural and psychodynamic approaches have something to offer in the treatment of eating disorders; yet, as neither has gained a clear eminence, CAT might be able to offset the weaknesses of one approach against the other.

The value of CAT in relation to the present study lies in the distinction between the formulation and intervention phases of therapy. Developing an 'understanding' of the problem is considered particularly important in the CAT model for clients who are ambivalent or 'pre-contemplative'. In the present study, participants felt uncomfortable with the timing of the intervention, in that a weight restoration program was underway before they had been given the opportunity to fully explore and understand the meaning of their eating disorder.

One of the main tasks of CAT is to identify the client's 'procedures' or ways of managing emotional difficulties. This can be equated to identifying the 'functional coping strategy' described in the present study. Having identified such procedures the therapist allows the client to decide whether he/she wishes to change and which problem they feel ready to revise.

CAT is a highly collaborative therapy which is intended to 'help foster the client's autonomy and mobilise her strengths in jointly tackling the target problems and underlying procedures' (Bell, 1996, p.7). This approach may be effective in tackling the current difficulties in treatment noted in this study, such as 'lack of negotiation' in terms of the approach and the 'timing' effects of not feeling ready to change.

In addition this approach combines insight related therapies which patients seem to desire (Clinton, 1996; Le Grange and Gelman, 1998) and noted by participants in the present study, whilst also combining collaborative treatment techniques to overcome the symptomatology of anorexia nervosa.

A research trial of CAT was conducted by Treasure *et al* in 1995. Thirty patients were randomly allocated to either 20 sessions of CAT or 20 sessions of educational behaviour therapy. At a one year follow up, two thirds of both groups had made significant progress, although the patients who had received CAT reported greater subjective improvement. The results are particularly encouraging given that the therapists had only received a basic training in CAT and had no previous experience with this therapy. Although CAT appears promising, the challenge remains for social factors to be addressed in the foreground, as opposed to the periphery of the therapy.

**b) *Organisational***

*Diagnostic/Labelling*

The results of this study suggest that the label of anorexia nervosa and the associated labels of mental health are pathologizing and unhelpful for the individuals suffering with the disorder. It seems appropriate therefore to ask what function do they serve?

The label 'anorexia nervosa' may well be helpful and useful for those who live with an anorectic patient. The label lessens their feeling of isolation in their struggle with the individual and it gives meaning to behaviour that might otherwise seem to be manipulative and irrational. But, for the individual the label isolates and distances the patient from seeking help and trying to understand the meaning of the disorder. The present series of interviews showed that they were not consciously aware of the onset of their disorder; consequently it would be only too easy for the starvation behaviour to be pathologized. However, what individuals appeared to be asking for in treatment was a different understanding of their disorder linked to their social world. This may represent a means of making unreasonable behaviour such as starvation more understandable.

The process of diagnosis and treatment seems to not only impact upon the individual's sense of control of their coping strategy, but it also seems to imply to the anorectic, that they have also lost control of their mind. As Reavey and Warner (1998) state 'Diagnosis...acts to sever the connection between the so-called 'symptoms' that women display and the real issues and experiences to which they relate' (p.5).

In addition once individuals had dropped-out of the service, the labels seemed to stick, in that they had subsumed the role expected of them. Because they had failed to respond to specialist services for anorexia nervosa, they may then be viewed by society, services and possibly themselves as the 'incurable anorexic'. When faced with similar stresses in everyday life, their non-eating behaviour was likely to be interpreted as an 'anorexic behaviour'.

Viewing anorexia nervosa as a pathology through diagnostic systems appears to perpetuate the notion of change at an individual level. Once a woman assumes the clinical identity of an anorexic it may be difficult for her to see the non-anorexic parts of herself. According to Szasz (1961) mental illness is nothing more than an individual deviation from a social norm and a diagnosis simply measures the extent of the deviation. Scheff (1966) believed the most important single factor in recognising mental illness is the degree of societal reaction. Therefore by analogy the diagnosis of anorexia nervosa may be viewed as a product of the individual over-stepping society's fine dividing line between aesthetically pleasing slimness and 'abnormal' thinness.

*Philosophy*

It is possibly no surprise that control emerged as a central concept given that the eating disorder service involved in this research conceptualised anorexia nervosa in relation to control. In addition, the philosophy of the service was to encourage the patient to surrender some control to the service in order to facilitate recovery. It is questionable whether this

tactic actually facilitates recovery, given the accumulative effect of the battle of control linked to the reactions of family, friends and society in general.

Although services seem to be aware of issues of control, this awareness may be hampered in therapy by the countertransferences described by Carr (1989). Therefore, the instinct to 'rescue' the individual may affect the therapeutic approach, without the therapist necessarily being consciously aware of this process. Therefore, training of staff who work with eating disordered patients needs to focus on how professionals can deal with such countertransferences. An emphasis on self-reflection in training may indeed be more valuable than technique focused training.

*Medical models and Contexts*

The findings from this research raise questions regarding the current emphasis of medical models within treatment services. The concerns centre around the contexts and approach of medical models and their influence on the individual's sense of control. The labels attached to many services are pathologizing and locate responsibility for change at an individual level, and the environment of the hospital creates a sense of passivity and vulnerability which may only serve to increase the patient's sense of lost control.

The current consensus in treatment programmes appears to focus on the dual nature of therapeutic interventions alongside weight restoration programmes. These two aims may be contradictory at certain times in treatment.

The survey by Newton *et al* (1993) found that many eating disorder patients had been successfully helped outside of medical contexts and with much less structured approaches. This may possibly be linked with the primary aim for patients to gain an understanding of their problems and be understood when entering treatment services (Hsu *et al*, 1992).

Treatment services at present primarily focus on the individual sufferer. Given that this study has drawn attention to the wider influences on drop-out, it seems appropriate to discuss how this might be dealt with in treatment. Family and friends are likely to be unaware of the effects their reactions have on the starving individual. Such reactions are understandable and may be reinforced by the current focus is on the individual and symptoms in treatment.

As families are increasingly isolated from the sufferer, their responses become increasingly desperate in an attempt to rescue the individual. Families may require the support of other families who are experiencing or who have experienced anorexia nervosa in their family. There is also a need for educating society in general about the possible meaning of anorexia nervosa. Opportunities for people to see beyond starvation and understand the wider social influences might help to create interaction with the individual as opposed to reaction to the symptoms.

*c) Clinical*

*Approach*

It is interesting that the primary service involved in this research was not solely based on the 'starvation model' i.e. that weight restoration was the primary goal of treatment. However, participants seemed to 'experience' this service (and others) as primarily focusing on the symptoms of their disorder. Whilst there now seems to be a consensus that psychological factors play a vital role in the onset of the disorder, they still seem to be considered secondary in the recovery process.

Participants were confused by the focus on the symptoms of weight loss, (such as food diaries, nutritional advice and weighing) because this was simply the symptom of a deeper cause which they wanted to understand. The setting of goal weights and the monitoring of meal plans within treatment parallels culture's objectification of "woman as body", thereby defining women's bodies for them rather than facilitating self definition (Kearney-Cooke, 1991)

Traditional treatment approaches fail in many respects, although a significant aspect is that in the process of using food restriction as a coping strategy, women have become 'experts' with regard to food and weight. They are fully aware of the intake required to maintain their coping strategy and they can easily see through treatment imperatives. As life had already become focused around food, treatment served to reinforce this coping strategy.

Clearly, weight gain will always be linked with successful treatment in anorexia nervosa. However, it may be the timing and approach to weight gain which determine the likelihood of drop-out from therapy. At times when self-starvation is life-threatening, weight restoration must be a first priority. However, it is vital that in the process an anorexic identity is not created for the individual.

Feminist writers have suggested that traditional treatments have the devastating effect of silencing women at the very time when they most need to discover themselves (Orbach, 1985; MacSween, 1993). These writers suggest that creating a space where women can speak about their understanding of food and their concerns in relation to it provides a way of cutting across the male discourse. Speaking about the meaning of the eating disorder in this way can her to develop the skills to become independent and empowered.

With regard to motivation for change, there is a growing body of literature (for example Blake *et al*, 1997) which substantiates the recommendation of therapists to negotiate and understand the experience of anorexia nervosa and the meaning of recovery. For example, clinicians are already advised in the literature to acquire a frame of reference that can help them understand the private experience of individuals with eating disorders, empathize with their distress at the prospect of weight gain, and acknowledge the difficulty of change (Vitousek and Watson, 1998). Orbach (1985) advocates that therapists acknowledge and respect the individual's need for control. In doing so a space is created in which she can be related to and allows the relationship to be defined in terms other than food and weight.

*Timing of interventions*

The admission versus acceptance category indicates that there is a clear difference in the patient's public acknowledgement of the disorder as problematic and the private protection of surrendering an effective coping strategy. In the early stages of treatment, patients may dutifully present with this public admission, which is trusted by the professional to indicate motivation to change.

This dilemma has implications for the timing of interventions; the introduction of tactics such as goal weights, which are confrontational to the coping strategy, may weaken motivation to engage. By setting aside time in the early stages to thoroughly understand the individual's experience of anorexia nervosa, the meaning of treatment and the individual's motivation to change, the therapist will ultimately have a clearer pathway to successful treatment. By negotiating such themes early on, responsibility and control are shared between therapist and patient and the meaning of recovery is made explicit and open to discussion.

Participants in this study valued contact with recovered anorectics. The complexity of the reasons behind this were not explored in depth within the interviews, although a number of hypotheses might be proposed. For example, given the creation of the 'them' and 'us' situation leading up to therapy, such contact may de-pathologise the coping strategy of food restriction as 'wholly bad'. It also links with the need to be understood which was common to participants in this study and others (Newton *et al*, 1993 ; Hsu *et al* 1992).

*The role of the therapist*

The demanding nature of therapeutic work with anorectics can present additional challenges to the most competent and experienced of therapists. The results presented here are not intended to be unnecessarily critical of existing therapeutic approaches or treatment techniques. In fact, what hopefully will arise from this research is a clearer understanding of the ways in which the therapeutic process can impact upon the interactional processes already underway; thereby drawing attention away from the therapeutic environment to the wider social context.

Sesan (1984) argued for the balancing of power within inpatient settings as therapists are frequently viewed as the experts which minimizes patients' self expertise. A number of participants had received nutritional advice early on in their treatment. At this time, their world was likely to be focused around food, and they were therefore the 'experts' of their own food intake. Such advice at this stage may not be beneficial when patients are unlikely to be motivated to change or are reluctant to give up this expertise.

Many interventions use a 'stepped' approach where nutritional and supportive counselling are provided as an initial intervention. If this is unsuccessful at resolving the issue, then more intensive treatments are employed. I would argue that where the individual's weight loss is not at a life threatening stage a reversal of this approach may well be more effective in the long term.

If therapists can first come to a shared understanding of the meaning of the disorder, then it may open up the possibility that it may function as a 'survival' technique, rather than a 'death wish'. In turn, this may enhance the therapist's creativity in finding alternative means of achieving the function. The therapist and patient may ultimately be able to construe the disorder in such a way that it has personal meaning and so that the pathologizing label of anorexia nervosa can be substituted by a more facilitative label.

Current practice in the treatment of anorexia nervosa advocates the need for the patient to be monitored with regard to weight, whilst also receiving counselling or therapy. Frequently, these two goals of treatment are managed by the same professional, which creates a dual role for the therapist. Such roles may be contradictory if one of our aims in therapy is to enhance a sense of self apart from that defined by the eating behaviour whilst also encouraging weight gain. Therefore, it may be more beneficial in the long term to have one therapist focusing on the therapeutic goals of treatment, whilst another professional monitors weight gain and food intake.

The treatment approach may therefore operate to consolidate anorexia nervosa as a coping strategy by focusing on the symptom of the disorder. The focus on the symptoms is not 'wholly' a bad strategy, but rather that this strategy may be more relevant at particular times within treatment. At present, the issue of weight is implicitly or explicitly in the foreground of all treatment approaches at present. I would argue that at some points in therapy, focusing on weight may be irrelevant if not damaging for the patient and may only serve to isolate the individual from using other treatments.

The 'life after drop-out' category highlighted a number of implications for the way in which drop-out or termination from therapy is dealt with by services. The initial ambivalence experienced by patients could be normalised so that it does not become another aspect of the individual's pathology. If the patient decides that treatment is not a viable option, ways of empowering the individual could be pursued in order to avoid the individual being burdened with the responsibility for recovery and reinforcing the 'anorexic' identity. The attribution literature (for example, Marlatt and Gordon, 1985) suggests that if relapses are attributed to unstable, behavioural and specific circumstances they will not be so detrimental in stagnating the process of recovery. For example, the transitory nature of the eating disorder as a coping strategy could be highlighted so that relapses are not viewed as a dispositional weakness.

## 4.4 Critical evaluation

*Validity*

It has been proposed that the validity of qualitative research refers to the plausibility or credibility of the researcher's assumptions (Flicke, 1998). An assessment can be made by questioning how far the researcher's constructions are grounded in the constructions of those whom he/she studied. If one accepts this notion of validity, then both the production and presentation of data are factors upon which the validity of research should be judged.

With regard to the production of data, one must consider the social desirability effect in research, which may be particularly relevant in the context of in-depth interviews.

Participants were asked to provide a narrative prior to interview, which enabled the researcher to assess the pertinent issues before the meeting. However, it is likely that even at this stage, participants had already formulated ideas of what my agenda was from written communications.

The issue of power seems to be particularly relevant in the discussion of this study. The participants' perception of me as a researcher, student or psychologist will have all had a bearing on our interaction. A deliberate attempt was made in the interviews to encourage the participants to feel comfortable about talking to me. Therefore my role in relation to the eating disorder service was discussed to ensure that they were aware that I was separate from the service. In addition, my personal characteristics in terms of age and sex, were hopefully beneficial in overcoming power relationships

In terms of the presentation of data, validity can be assessed by questioning the internal coherence of the argument presented. So, for example, are the interpretations of the researcher reasonable?

*Respondent Validation*

Communicating the findings of the research to the participants is one way in which the plausibility or credibility of the emergent theory can be evaluated. This is not without problems and one has to be aware of the power relations underpinning the outlooks of both respondents and participants (Henwood and Pidgeon, 1995). Respondent validation in this

study had a dual purpose. Firstly to provide feedback to participants and express my gratitude for their participation, and secondly to inform the emergent theory.

Five participants responded to a letter outlining the results (see appendix 11) and the participant's feedback is included in appendix 14. The response to the model overall seemed to be positive. It was a process with which individuals appeared to identify and participants were willing to provide other examples to substantiate the core categories. As no one provided additional information to directly challenge the model, reformulation of the findings were not considered necessary.

Eliciting feedback through written communication did have its limitations. Firstly, it is difficult to provide a concise and understandable account of the model without losing its complexity, and secondly, participants were prompted by a limited number of questions. Clearly some participants were willing to provide a considerable amount of feedback and this was difficult within the confines of the space I had provided in the feedback form.

It is possible that an interview (as opposed to a letter) may have been more productive in developing the model further. An alternative approach considered was to present the findings directly to the group of participants and record their feedback. However, due to limitations of time and the complexity of arranging a meeting convenient to all, this was not considered to be viable option.

*Triangulation*

Triangulation is frequently used in qualitative research as a strategy for validating results. In the present study it was also used to enrich the production of data by increasing the scope, depth and consistency of the methodology.

Denzin (1989) distinguishes four types of triangulation.

1) Data triangulation refers to the use of different data sources such as distinctions between time, persons and space. This can be equated to the theoretical sampling strategy inherent in the grounded theory model. In this study I was fortunate in obtaining a sample which varied considerably in terms of their duration in the eating disorders service (which ranged from assessment to over one year), the type of treatment received (with regard to therapeutic approach) and the context of their treatment (inpatient, outpatient, through secondary and tertiary services).

2) Investigator triangulation where different observers or interviewers are employed to detect or minimize biases resulting from the researcher as a person. The qualitative support group was particularly useful in providing a forum for other researchers to debate and challenge the emerging theory and provide alternative conceptualisations. In addition, the research diary and regular supervision helped to illuminate my pre-conceptions.

3) Theory triangulation is the third type of triangulation in which the data are approached with multiple perspectives and hypotheses in mind.

4) The last type Denzin (1989) names as methodological triangulation. Narratives and interviews were employed as methods of data collection in this study. The aim of this

procedure was to allow the participants to set the agenda before meeting. Although an

interview schedule ensured that there was some uniformity in the questions asked

across interviews, the narratives enabled me to focus on particular issues in more detail.

Denzin (1989) advocated that the 'triangulation of method, investigator, theory, and data

remains the soundest strategy of theory construction' (p.236).

*Reliability*

As previously mentioned, traditional notions of reliability which concern the replicability

of data are misleading as the phenomenon under study in qualitative research is constantly

changing. Thus, the criterion of reliability has been reformulated in the direction of

checking the dependability of the data and procedures which can be grounded in the

various qualitative methods (Flicke, 1998).

Within the confines of this thesis, efforts were made to ensure that clear documentation of

data was made in order to assess the research process and the interpretations made. In

addition, throughout the study a paper-trail of the research process (through memos,

definitions, research diary and flow diagrams) were all filed and dated in accordance with

the sequence of the research. Unfortunately, due to the vast quantity of this information, it

is not possible to include this within the thesis, although some examples have been

provided.

The grounded theory method has a 'built-in' reliability check in terms of the constant comparative method. Therefore, each category was tested by checking it against passages in the same text and other texts to assess similarities and differences.

*Generalisability*

Generalisability in qualitative research refers to an analysis of the domains to which the findings may be applicable (Flicke, 1998). Therefore, qualitative researchers have analysed which contexts their findings may be transferred to without losing the true meaning of the findings. This is generally referred to as 'theory-based generalization' (Hammersley, 1993).

An attempt has been made to describe the research context of this study, so that other readers can assess the transferability of the model to other contexts. This research has identified links with findings from a diverse range of therapeutic settings. In particular, contexts where an individual's behaviour is viewed as extreme and outside of the 'norm', then a similar interactional process may ensue, which may accumulate in drop-out within the treatment context.

*Theoretical Sampling*

Sampling of negative cases is considered to be beneficial in providing a conceptually rich and dense theory (Henwood and Pidgeon, 1992). Limitations on this were the number of participants willing to participate in this research. Fortunately, a good response rate enabled participants to be selected in terms of theoretical concerns. For example, having

initially interviewed a number of former outpatients who had talked about the focus on symptoms in treatment, I was keen to develop an understanding of these themes with patients who had received inpatient treatment. This enhanced my understanding of the relationship between the battle between the individual and others regarding the perception of the disorder.

Rennie *et al* (1988) have suggested that saturation of categories (i.e. when no new themes emerge from data collection) generally occurs after the analysis of five to ten protocols. In this study, data collection ceased after the seventh interview, and fifth narrative. However, it is possible that more themes may have emerged with further data collection. Pragmatic considerations regarding the limited amount of time available for this study also influenced this decision.

The participants in this study were accessed through one service, although a number had experienced treatment at other specialist and non-specialist services. It may have been useful to have accessed a wider range of treatment services in order to assess discrepancies in relation to context, philosophy and approaches of various services.

Biases relating to the self-selected sample of this study must also be considered. For example, they were all likely to be self-reflexive, and have particular issues which they wished to discuss and may therefore not be representative of the general population of patients who drop-out. Although males were not excluded from participating in this study, the self-selection of the sample has resulted in this study focusing exclusively on the

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experiences of females. The results from this study are therefore confined to the experience of females in services for anorexia nervosa, and cannot reliably be generalised to male anorectic patients. In addition, it may have been useful and interesting to interview patients who successfully engaged in treatment and contrast their experiences with participants in the present research.

*Negative cases*

This model cannot offer the definitive explanation of anorexia nervosa. As the focus of the study was on drop-out, some aspects of the disorder were investigated in more detail than others. Therefore, there are clearly going to be gaps which require further research. Some sections of the accounts may represent 'negative cases', or instances where the model does not fit. It is essential to explicate these in assessing the possible weaknesses and gaps in this model, so that they may be dealt with in the future.

For example, in the help-seeking section, the pathologizing labels of the 'mental health' service seemed to be particularly off-putting for most participants. However, participant number 6 viewed anorexia nervosa as a mental illness which she felt was poorly recognised by the public. In accessing mental health services and receiving a diagnostic label, it appeared she was able to make sense of her 'illogical' behaviour. In this instance, the label of anorexia nervosa and mental illness were embraced rather than rejected. Therefore further research into the meaning of the label of anorexia nervosa may be required in order to assess the function of this.

*Grounded Theory*

Chapter 2 outlined the method of grounded theory and explored reformulations of the model based upon epistemological criticisms. The present research incorporated a social constructionist revision of grounded theory into the analytic process. Therefore, an attempt was made to remain reflexive and aware of my role as a researcher and my influence on the emergent theory.

Reason (1994) cited in Mcleod (1996) described qualitative research as a process of inquiry that fundamentally relies on the 'creative sense-making' ability of the researcher. From this stance, methods such as grounded theory can be seen merely as a way of structuring this ability to make sense. Furthermore, Henwood and Pidgeon (1992) note that 'methods are not so much valid in and of themselves, but will be more or less useful for particular research purposes' (p.100).

As a novice researcher in qualitative methods, I found grounded theory to be useful in providing explicit skills and techniques to aid theory generation. The specific procedures of Strauss and Corbins' (1990) model provided a means of making sense of vast quantities of data, although transgressions from their model were deemed necessary and have been noted.

A social constructionist revision of grounded theory was considered to be appropriate for assessing the meaning of drop-out in relation to wider contexts. Participants' accounts were not taken to be objective facts or truths, but as experiences based upon the influences of culture and society. For example, in terms of the current social climate, control is

particularly pertinent in the general research literature. There has been a gradual shift in the research to assessing the 'consumer's' view of treatment services and subsequently concerted efforts have been made to enhance the degree of control that patients have over their own health.

The review of the literature in chapter 1 questioned the current influence in the literature on the individual. An approach such as social constructionism asserts that people are the product of social processes and conditions which are constantly changing throughout history (Burr, 1997). This approach seemed particularly relevant in researching anorexia nervosa, where the meaning of the disorder has endured considerable scrutiny and change over time. Therefore, the results from this study are not considered to be so much of a 'discovery' as one conceptualisation of anorexia nervosa.

One of the difficulties posed by social constructionist research is that there are no criteria for judging the 'truth' of different constructions or accounts. In addition, social constructionism seems to pose a threat to the discipline of psychology. As Burr (1997) suggests, 'It claims to be able to explain the social world without recourse to any concept of the individual person or psyche' (p.11).

*The model*

As previously mentioned, the concept of control is not new or novel to research into the causes or cures of anorexia nervosa. Indeed, the participants themselves seemed very aware of its application in this area, which may suggest that it may be accepted as a lay

term which links anorexia nervosa with a pathological need for control. Wren and Lask (1993) suggest that the concept of control may be a particularly useful shared theme which could bring together different perspectives on anorexia nervosa, and so produce a more integrated literature.

There are possible dangers in reproducing this label, especially when there are so few benefits in utilising an existing concept in an area where there is already a great deal of pathologizing labels attached to the disorder. In addition the ambiguity surrounding the concept may create more confusion than it aims to resolve.

This was taken into consideration when formulating the core model and efforts were made to be creative in developing new conceptualisations. However, the participants in this study did not seem to be employing it in the conventional manner and as the emergent model revealed, it was seen as an interpersonal matter as much as intrapersonal. It was a concept with which the participants identified and which appeared to have personal meaning. Through this concept, they were able to make sense of their 'unreasonable' behaviour. To impose yet another external label on the meaning of anorexia nervosa may too have more damaging consequences.

*Reflexivity*

Reflexivity is perhaps the most distinctive feature of qualitative research. It is an attempt to make the research process explicit, in terms of both the production and analysis of data. According to Wilkinson (1988) (as cited in Banister *et al*, 1994), reflexivity should involve

thinking about oneself and about one's research. Banister *et al* (1994) suggested that researchers must recognise that they inevitably have 'biases, interests, predilections, values, experiences and characteristics which affect their research findings and also their interpretation of it' (p.150). Therefore, the influence of the researcher is centralised rather than marginalised so that we can become critically aware, and ultimately enhance the validity of our research.

An attempt has been made in this study to remain reflexive to my own values and assumptions. This has been monitored through a field diary, the qualitative support group and individual supervision. In addition the use of the first person in the presentation of the thesis, may help readers to distinguish and judge the researcher's own interpretations.

Transcribing each interview increased my awareness of leading questions based upon my presuppositions and this in turn helped to plan subsequent interviews. For example, initially I was aware of using the word 'control' and tried to avoid this line of questioning. I was also aware of using therapeutic techniques within the research setting, although I found this much more difficult to refrain from incorporating in the interview.

*Personal experience of the research*

This research was particularly rewarding as it gave me a privileged understanding of the accounts of these women. Denial in self reports of anorectics has been raised as an issue in research and this concerned me initially as not only was I choosing a difficult population, but a sample known to be protective over their experience.

Therefore, I was surprised at the response I received to my letter inviting them to participate in this study, and I was also impressed by the quantity and quality of information that they were willing to share with me. When asked why they had agreed to participate in this study, the reasons seemed to be about being understood and heard and so that ultimately services can understand their experience of treatment, and adapt services as necessary.

I was also aware of the privileged roles both myself and the participants had in the research process. There were no consequences for either in participating in the research. I was aware that my role was not to 'treat' the participants and they were also aware that I did not expect them to change in any way. The effect of this is that we could both explore the meaning of anorexia nervosa from a new perspective.

It is interesting also to explore how the participants may have experienced this research. In the wind down section of the interview schedule, participants were asked how they found the questions. The answers varied quite considerably, and seemed to reflect the way in which the interaction itself had constructed the data. For example, in some interviews, participants began by confidently stating that they had no regrets about their decision to drop-out, to questioning whether they were in need of more help. Some seemed to find it emotionally distressing as they recounted traumatic experiences and once again appeared to be (re) –constructing events.

Grafanaki (1996) has suggested face-to-face interviews can promote the building of a 'research alliance' between the researcher and participants, in the same way that a therapeutic alliance can be built between a therapist and client. I would support Grafanaki's (1996) view that qualities developed through clinical training, such as active listening, accurate understanding, warmth, acceptance and genuineness are of major importance in promoting rapport between researcher and participants.

I was aware of some of the difficulties in using a qualitative methodology and the possible conflict with my training in a primarily scientist-practitioner model. Not only was adequate support difficult to find, but I was also aware of the research being judged against traditional scientific standards.

I have found that this research has had a considerable impact upon my clinical work. It has enhanced my awareness of the functional nature of a range of psychological disorders. I have been more cautious in ascribing clinical labels and have begun to assess treatment in a much more 'systemic' way.

## CONCLUSION

The analysis of this study elucidated a process which was referred to as 'the interactional model of control'. This model emphasised the interactions between the anorectic and family, friends, and professionals which affect the individual's sense of control. Such interactions included the battle of the perception of the disorder as either functional or dysfunctional, the efforts of the individual to maintain the coping strategy and others attempts to change the individual's problematic behaviour.

The cycle revealed the accumulative effects of such interactions within the context of treatment which resulted in the individual dropping out of services to maintain a sense of control over the perception of the disorder, one's identity and the coping strategy. The implicit and explicit processes within treatment were identified which influence the individual's sense of control and contribute to the battle for control already underway.

Chapter 1 identified gaps in current conceptualisations of drop-out from services for anorexia nervosa. Despite a general consensus that eating disorders are multi-factorially determined, conceptualisations of drop-out have been directed at very specific aspects of treatment or the individual. There appear to have been few investigations of the anorectic's own experience of treatment. The wider social influences identified as precipitating factors in terms of aetiology have been neglected thereafter in the research.

This study has endeavoured to fill some of the current gaps in conceptualisations by attempting to understand the complexity of the process of drop-out. Therefore, aspects

such as the meaning of anorexia nervosa were integrated with an analysis of the experience of treatment.

In terms of future directions for research, further exploration is required in terms of the subtle influences of context and labels on the process of drop-out. The timing and approach of treatment are beginning to be addressed in the research literature, possibly because these are more accessible to change in the current climate of services.

Given the interactional nature of control identified in this study, it would be interesting to explore the meaning of anorexia nervosa for the family and society in general. Research has begun to address the experience of therapists, although this is still in its infancy. In addition a further focus on lay people's perceptions of anorexia nervosa would be interesting. For example, an exploration what informs people's perceptions of anorexia nervosa as 'wholly' dysfunctional may help to develop further the interactional cycle of control.

In conclusion, it appears that until services recognise the social production of symptoms, they will continue to perpetuate the conditions in which people risk their lives in order to survive their lives.

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# APPENDIX 1

## DSM IV CRITERIA FOR ANOREXIA NERVOSA

- Refusal to maintain body weight over a minimal normal weight for age and height (e.g., weight loss leading to maintenance of body weight 15% below that expected; or failure to make expected weight gain during period of growth, leading to body weight 15% below that expected)

- Intense fear of gaining weight or becoming fat, even though underweight.

- Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.

- In postmenarchal females, amenorrhea, i.e., the absence of at least thre consecutive menstrual cycles. (A woman is considered to have amenorrhea if her period occurs only following hormone, e.g. estrogen administration).

*Specify type:*

**Restricting Type:** during the current episode of Anorexia Nervosa, the person has not regularly engaged in binge-eating or purging behaviour (i.e. self-induced vomiting or the misuse of laxatives, diuretics or enemas).

**Binge-Eating/Purging Type:** during the current episode of Anorexia Nervosa, the person has regularly engaged in binge-eating or purging behaviour (i.e. self-induced vomiting or misuse of laxatives, diuretics or enemas).

# APPENDIX 2

## TIME LINE OF RESEARCH PROCESS

| | |
|---|---|
| **JULY 98** | Submission to research ethics committee in NHS trust |
| **AUGUST 98** | Re-submission to ethics |
| **SEPTEMBER 98** | Ethical approval granted<br>Invitation letters sent to patients |
| **OCTOBER 98** | Data collection - narratives<br>Open coding of narratives<br>Planning of interview schedule |
| **NOVEMBER 98**<br>**DECEMBER 98** | Data collection – interviews<br>Transcription of interviews<br>Open coding of interviews |
| **JANUARY 99** | Open coding |
| **FEBRUARY 99** | Axial coding<br>Selective coding<br>Interactional model of control emerged |
| **MARCH 99**<br>**APRIL 99**<br>**MAY 99** | Feedback to participants<br>Writing up |

# APPENDIX 3

## PARTICIPANT 1

**Interview number:**        1

**Narrative number:**        3

Participant 1 was 22 years of age at interview. She was seen at her University Halls of residence where she was studying for a degree. The onset of her disorder occurred around the age of 14 and she first received treatment from a child service at the age of 16. Her mother accompanied her to the appointments and she dropped out after one year of treatment. She attributed this drop out to her own ambivalence about therapy, which was exacerbated when there was a change of therapist who she perceived as threatening.

Participant 1 continued to experience difficulties with her eating and sought help in the first year of her studies at university. Her parents persuaded her to take one year out of college to seek help for her eating disorder. She was 19 when she was assessed by the Eating Disorder Service and waited approximately six months for therapy. Participant 1 dropped out of therapy after two weeks as she felt she was uncertain about change. Drop-out was negotiated with the therapist and she has not received any further treatment. She was interviewed for this research 6 months after dropping out of the service. Participant 1 reported that she was not fully recovered, and from observation looked underweight.

## PARTICIPANT 2

**Interview number:**        2

**Narrative number:**        1

Participant 2 was employed as an administrator and was 32 years of age at interview. She was interviewed at home where she lived with her four year old daughter. Her eating disorder was triggered after a road traffic accident which resulted in her experiencing post traumatic stress disorder and depression. She received counselling from a community psychiatric nurse, prior to being referred to the Eating Disorders Service at the age of 30.

Participant 2 waited approximately 10 months for assessment and dropped out after the third assessment session. This was negotiated with the team member, after she expressed that she was reluctant to comply with the target weight. She had left the service 6 months prior to being interviewed for this research and had not received further treatment in the meantime. Although she reported considerable progress since dropping out, she continues to feel vulnerable to eating problems. Physically she looked slightly underweight at interview.

## PARTICIPANT 3

**Interview number:**                    3

**Narrative number:**                  Narrative not completed

Participant 3 worked as a dancer, and the onset of her eating problems commenced during her training when she was around 17 years of age. She was interviewed at the Eating Disorders Service at the age of 23. She was referred to the service by her G.P. under pressure from her parents. She attended two sessions and did not negotiate drop-out. A number of factors seemed to contribute to her decision to drop out, including the 'mental health' label of the service, ambivalence about change, and the pressures to remain thin from the dance school. She was interviewed 18 months after dropping out of the Eating Disorders Service. She had not received treatment following drop-out and looked slightly underweight at interview.

## PARTICIPANT 4

**Interview number:**                    4

**Narrative number:**                  Narrative not completed

Participant 4 was referred to the Eating Disorders Service after having previously seen a counsellor at university. She was on the waiting list for approximately three months before being offered treatment at the Eating Disorders Service.

The participant linked the onset of her disorder (at approximately 16 years of age) to her family environment, where her father was physically abusive and her mother also had an eating disorder. Participant 4 attended therapy for the longest duration of time of all the participants; one year, in which she felt she had made considerable progress. Drop-out occurred after a break from the therapy sessions during her university vacation, which was 6 months prior to being interviewed for this research. Whilst at home, her eating deteriorated and she felt reluctant to go back to therapy and admit to relapsing. At interview, participant 4 appeared to look very healthy and an 'average' weight. However, she continued to feel susceptible to anorexia nervosa and felt she would not be fully recovered until she moved out of the family home.

## PARTICIPANT 5

| | |
|---|---|
| **Interview number:** | 5 |
| **Narrative number:** | 5 |

At interview, participant 5 was 22 years of age and had suffered with anorexia nervosa since she was 17 years old. She voluntarily mentioned that she weighed just 4 stones and ten pounds at interview and had just been discharged from a psychiatric hospital where she had been sectioned as an inpatient for one year.

Her eating disorder appeared to have been triggered by bullying when she was studying a child care course at college. Initially she was referred by her G.P. to a psychiatrist who

then referred the family for therapy. Her weight decreased rapidly and after a battle between her parents and her local health authority regarding funding, she was admitted to a private, specialist eating disorder clinic. What seemed to ensue was a struggle of maintaining the weight gained from the clinic at home and she was re-admitted on several occasions.

At the age of 20 she was admitted to the Eating Disorder Service as a voluntary inpatient for two months. She dropped out of the service after 5 months (17 months prior to being interviewed for this study), and this seemed to be due to her inability to cope with the rapid weight gain.

## PARTICIPANT 6

**Interview number:**          6

**Narrative number:**          Narrative not completed

Participant 6 was 43 when she was interviewed for the research, and had been referred to the Eating Disorder Service by her G.P. after she had started to lose weight. She had, however, attended the Eating Disorders Service approximately twenty years previously, and she dropped out on this occasion after one year of therapy.

Interestingly, participant 6 thought she had been asked to be interviewed regarding the initial drop-out, as she did not consider herself to have dropped out after her second

consultation with the service which was 6 months prior to being interviewed. The reason for this confusion, seemed to be that participant 6 did not consider her eating to be problematic, and instead had attended the service with the hope of accessing generic mental health services with a view to receiving help for chronic depression. Therefore, she only attended for two assessment sessions, before returning to her G.P. to ask for specialist help for her depression. Participant 6 has not received any other help since leaving the Eating Disorders Service, and described herself as partially recovered from anorexia nervosa. At interview she looked an 'average' weight for her height.

## PARTICIPANT 7

| | |
|---|---|
| **Interview number:** | 7 |
| **Narrative number:** | 2 |

The onset of this participants' disorder occurred around the age of 18, shortly after the birth of her second child. She was assessed by a psychiatrist at the age of twenty regarding her eating problems, and shortly after was admitted to a psychiatric ward for 6 weeks. She received counseling from a Community Psychiatric Nurse before she was referred to the Eating Disorders Service at the age of 20.

She waited four months for therapy and dropped out after four weeks. This was not negotiated and attributed to a combination of reluctance to change, dislike of therapist and disagreement with the target weight.

Following drop out, she went to see a hypnotherapist who she described as extremely helpful in overcoming her low self-esteem. At interview (18 months after dropping out) she looked underweight and reported that she felt she would never be totally recovered from anorexia nervosa.


## PARTICIPANT 8

**Interview number:**          Interview not conducted

**Narrative number:**          4

The onset of participant 8s' eating disorder occurred around 16 years of age. She was 20 years of age at the time of the referral to the Eating Disorders Service and waited six months for therapeutic intervention. She was monitored in the meantime by an occupational therapist.

She dropped out of therapy after seven sessions as she felt she was unable to give up her only source of control. Shortly after drop out, she became pregnant and concern was raised regarding her eating disorder by her midwife, when she had only put on two pounds in weight at five and half months into her pregnancy. An urgent referral was made for systemic therapy at a private unit outside of the region. The appointments appeared to have been very beneficial in providing advice, guidance and support for herself and her husband. For a while, the eating problems seemed to improve dramatically, but were triggered again

when her husband emigrated. She was, however, hopeful that she could continue her recovery when she joined her husband abroad. Participant 8 had dropped out of the service twelve months before participating in this study.

## APPENDIX 4

**The Anorexic Regime for Inpatients**

The aim of this booklet is to provide you with information about what your treatment in hospital will involve. We have tried to anticipate the kind of questions you might want to ask, but please feel free to approach members of the team for any further information you require.

*The Ward*

**** Ward is an acute admission ward within the **** Unit on the site of **** Hospital. The ward has 36 beds, 6 of which are set aside for the treatment of people with eating disorders. The ward has a friendly, informal atmosphere but is usually full and busy.

*The Team*

During your stay on the ward, and later in the day programme, you will be cared for by a multidisciplinary team consisting of nurses, doctors, psychotherapists, occupational therapists and psychologists. This is a teaching and research unit so you may be asked to see medical students and staff engaged in research.

The consultant in charge of your care is Dr. ****. One of the team will be allocated as your main therapist. Each patient is also allocated their own ward nurse known as a Primary Nurse, and when you start the day programme you will be given a keyworker there. We hope your Primary Nurse will come to be someone you can trust, who will plan your care, provide you with support and help you deal with any matters that concern you. Your Primary Nurse will meet with you regularly to assess your needs, difficulties and progress.

In addition each patient also has several Associate Nurses who will look after you in the absence of your primary Nurse. However, it is important to remember that *all* the nursing team are there to provide help and support.

*Arrival and Admission*

When you first arrive on the ward a nurse will introduce themselves to you and ask you for some information such as your address and next of kin. They will also try to

answer any questions you might have about your treatment. You will be asked to change into your night wear. We would like you to remain in this until you start the day programme. A ward doctor will see you so that they can establish an accurate assessment of your physical health and document a basic history of your problems.

*The Regime*

In order to help you feel secure during the day we have developed a set of clear guidelines for the management of your weight and eating. These guidelines are collectively known as the regime. Some of these rules may seem strict, but in our experience they will help you to feel safe.

On admission you will be weighed and your height measured. Thereafter weighing takes place twice weekly – on Sunday and Wednesday mornings. Your target weight will be determined within the first week or two of your stay.

Our aim is that you will reach your target by gaining about one kilogram a week. For this you are prescribed a diet from the normal hospital menu. You have some choice but in general the idea is that you hand over control of your weight and eating to staff.

Special diets such as vegetarian are allowed but only if agreed prior to admission as dislikes. We ask you to choose a list of up to five foods you dislike. Certain foods are not allowed. These include bread, potatoes and pastry. Other requested dislikes may also not be allowed – staff have the final say. You have to have either butter or flora on your bread.

You will begin on a lower calorie diet but that is likely to be increased within a week or so. If you are not managing to gain 1kg/week, this will be discussed with you and the team and we may need to plan an increase in your diet, either by the addition of extra food at meal times or as snacks between meals. Most people need additions to the basic diet.

We then order you a planned menu and bring your food to you. A member of staff will sit with you when you eat to provide you with supervision, support and encouragement.

You will also be given a set number of drinks as part of your diet. You may bring your own mug and tea/coffee if you prefer; we will keep these for you. You have some choice in what you drink but are not allowed diet or other special low calorie drinks. Meals/snacks/drinks should be delivered to you on time and correctly. However you must remember that it is a complicated system, staff are human and make mistakes and also that **** Ward can be extremely busy and things may be occasionally late.

As you have agreed to treatment there is an expectation that you will eat and drink your prescribed diet. You are also expected to not eat or drink anything that is not prescribed or use any other methods to control your weight. However we acknowledge that you may find this very difficult and hope that you will feel able to discuss any problems you are having with a member of the team, but particularly your Primary or Associate Nurse.

We will try and work through any problems with you, but if it appears that things are turning into a battle we may suggest you take some time out to think things over. This is to provide you with an opportunity to return and make a fresh start if you wish.

*Visitors*

Visitors are welcome to the ward between 10.00 a.m. and 9.00 p. However it is best to arrange visits when you are not otherwise engaged. We suggest you ask visitors not to come at mealtimes, i.e. before 10.00 a.m., between 12.00 – 2.00 p.m. and 5.30 – 7.00 p.m. Once you are attending the day programme you will be occupied from 10.00 a.m. to 3.45 p.m. weekdays (2.15 p.m. on Wednesdays).

Visitors should be asked not to bring any food or drink unless it will be part of your diet when it should be handed into staff. While in the sideroom visitors are allowed in your room; otherwise they may be seen in the day or quiet room.

*Telephones*

There are several pay phones in the unit and a phone which takes incoming calls only on the ward. You may usually take incoming calls when you are free. You are only allowed off the ward to make calls when this has been agreed and then only on Mondays, Thursdays and Saturdays. You will not be allowed to make calls while you are still in the sideroom, but we can pass on messages if you wish.

*Leave*

While on the regime you will not be allowed any leave home until late in your stay. In our experience any break in treatment earlier is likely to be disruptive and delay your progress.

*Smoking*

If you smoke, arrangements will be made for you to use the smoke room at specific times.

*Medication*

You may be prescribed medication as part of your treatment, with your agreement. These are given out from the drug trolley by the clinic at about 8.30 a.m., 12.30 p.m. and 4.30 p.m., although may be given at other times if necessary.

*The Sideroom*

On admission you will be in a sideroom. This is so that our supervision of you can be greater initially, and so that you can feel as safe as possible. You may bring in your own things to make the room feel more comfortable. Electrical equipment such as T.V.s is allowed but will need to be checked by a hospital electrician before you can use it.

The hospital provides bed linen and towels but we ask you to bring in your own toiletries. The time spent in this room varies, but is usually about two weeks. During this period we ask you to *stay in the room*. You will have your meals supervised within the room. A commode will be provided and the U-bend removed from the sink and replaced by a bowl. We will empty these for you. This is to help you combat any urge you may have to dispose of food and drink. It helps us keep accurate records of your fluid intake and output.

You are allowed a bath or shower each day but will need to be supervised so this may not always be possible. You can use the ward's laundry room with permission and/or supervision – you will need to bring your own washing powder. If things are going reasonably well then the next step is to move into the shared dormitory known as the ****.

*Male patients*

If you are male things are a little different from now on. Much of what happens will be the same but obviously you do not share the same dormitory. You may remain in the sideroom longer but at the same point you will move into a dormitory shared with other male patients not on the regime. You may also have longer in the dayroom in the evening if agreed by the team.

*The* \*\*\*\*

This is a five bed dormitory you will share with others on the regime. (Though at times beds may be occupied by people not on the regime). You will remain part of this dormitory for the rest of your stay, but that stay will be divided into several parts. From when you first move in you may use the toilets, bathroom, laundry room freely. All meals will be eaten jointly in the small dining room on the same corridor with one nurse providing support and supervision. We ask you to finish your meals within 35 minutes and then remain in the dormitory for a further 45 minutes after the meal to help you avoid any urge you may have to dispose of food.

Visitors may now be seen in the day or quiet room and you may also spend specified time in the day room in the evenings. Visits by those in the \*\*\*\* to those in the sideroom may be made only at the discretion of staff. Otherwise we expect you to *remain in the dormitory.*

*Day Programme*

Again if things are going as well as we hope then you should start attending the day programme. This is likely to be about 5-7 weeks into your admission. Staff from the day programme will meet with you and your nurse at least a week before you start, to explain the programme in more detail and answer any questions you may have.

Once you start attending you may wear loose casual clothes rather than night wear. (Remember you will still be some way from reaching your target). The staff from the day programme will fetch you from the ward at 10.00 a.m. and return you at 3.45 p.m. During those hours you may not have visitors or go off to use the phone. You will have your lunch at the day programme.
There may also be outpatients attending the day programme some of who may not have had a period of admission. They may have different boundaries but will still be expected to be making progress. As you move towards your target our aim is that you begin to take back some control. Things may be different from now, depending on where you live.

*Early Discharge*

If you live locally and would be able to attend as a day patient, and if it appears appropriate to the team, then you may be discharged several weeks before you are likely to reach your target weight. You are then entirely under the care of the day programme staff ( as we hope you have established a good relationship with your ward nurses, they will usually maintain some contact with you). If appropriate you might have some home leave just before discharge.

*Remaining an inpatient*

If you are unable to attend as a day patient, for instance, if you are from outside ****, then we ask you to stay as an inpatient until some time after reaching your target. However, your care at the day programme will offer the same kinds of things as if you had been discharged. Once you have been discharged you may continue to see your therapist regularly as an outpatient.

*Individual therapy*

If you have been seeing a therapist prior to admission you will continue to see the same person during your stay. Otherwise you will be introduced to a therapist as soon as possible. As soon as you progress through your treatment you ma have new experiences and feelings as you attempt to understand and come to terms with the difficulties entangled with your weight and eating. Your therapist in particular, but also others involved in your care, will aim to help you develop new ways of coping with the emotional changes you may experience as you gradually gain weight.

*Family Meetings*

You will be given the opportunity to have family meetings. This is to allow discussion between yourself, your family, and members of the team with the aim of promoting a shared understanding of the emotional changes that affect you and those closely involved with you.

**** *Meetings*

Once a week all inpatients on the regime meet together with staff. This is to provide an opportunity to discuss any general matters, particularly of living together as a group.

*Finally*

We know that you will have struggled with your decision to consider inpatient treatment, and you may be wondering if you are going to find it too difficult, and also whether people are going to understand. This is probably one of the most difficult things you have had to do, but you are not doing this alone.

# **APPENDIX 5**

Miss A C Payne

Clinical Psychologist in Training

10 September 1998

Dear Miss Payne,

**Understanding the experience of treatment for anorexia nervosa: The perspective of patients who drop-out of services – our ref. No. 5152**

Thank you for your letter responding to the issues raised by the **** Ethics Committee in connection with your application to undertake the above study.

You will be pleased to know that the **** Ethics Committee has now approved your request to undertake the above-mentioned research.

Your attention is drawn to the attached paper which reminds the researcher of information that needs to be observed when ethics committee approval is given.

Yours sincerely

Chairman

**** Ethics Committee

# APPENDIX 6

Dear ****,

**"Understanding the experience of treatment for anorexia nervosa"**

I am writing to you to ask for your assistance in a project which I am currently conducting as part of a doctorate in clinical psychology at the University of Leicester.

I am researching the treatment that former patients received for their eating disorder. In researching this, the aim is that the findings will help professionals in their approach to treating patients with anorexia nervosa and milder forms of eating disorders in the future.

I am therefore asking former patients like yourself if you would be prepared to attend an interview where we would discuss your experience of treatment, your contact with the Eating Disorders Service and how things are for you now. This will take approximately one hour and will be tape recorded to ensure that I do not miss any details from our conversation.

In addition to the proposed interview, it may be that you would also feel able to put something on paper about your experiences. For example, this might take the form of a short story or account of your experiences. I would like to stress, however, that this would depend on your preference, as not everyone is comfortable with writing things down. If you are interested in participating, we can discuss at a later date the most suitable way for you to express your views.

Your name and personal details will be kept confidential and for the purpose of the research report or publications, any reference to your story or interview will be changed to protect your identity. The content of your story and interview tape/transcript will not be shared with other members of the eating disorders team and your involvement in this

project will not affect your future treatment at the Eating Disorders Service. You may also withdraw from participating in this project at any stage.

I do hope you will feel able to give up some of your time to help me with this study, which should help our understanding of the best way to help people with eating disorders such as anorexia nervosa. Please sign and return the consent form in the pre-paid envelope if you would like to participate.

I look forward to hearing from you.

Yours sincerely,

Alison Payne (Bsc Hons)
Clinical Psychologist in Training.

## APPENDIX 7

## CONSENT FORM

**" Understanding the experience of treatment for anorexia nervosa"**

The nature and purpose of the research project have been explained to me. I understand that any information which I give will be treated with great confidentiality. Any quotations included in the research will not identify me as an individual.

I give my consent to the recording of the interview and understand that the interview tapes will remain confidential and will not be made available to any other professional within the service except the researchers involved directly with this research project. I am also aware that I may be asked to provide a written account (or other suitable method) of my experience of anorexia nervosa.

I understand that my decision to participate will not affect my future treatment and I can withdraw from the research at any stage.

---

I give my consent to be interviewed and for the interview to be audio taped and transcribed.

Name  (please print): ....................................

Name  (please sign):  ....................................

Date:                   ....................................

Please return one copy of the signed consent form to;

Alison Payne
Clinical Psychologist in Training

Please keep the second copy of the consent form for your own information.

# APPENDIX 8

14.9.98

Dear Ms ****,

I am writing to you to ask if you would be prepared to participate in a research project currently being undertaken by a Clinical Psychologist in Training at the Eating Disorders Service.

The aim of the project is to explore the experience of treatment for eating disorders from the perspective of former patients of the Eating Disorders Service here at **** Hospital.

I have suggested that as a former patient, you may be willing to participate in this study which will hopefully help professionals in their approach to treating patients in the future.

Enclosed is an information sheet which provides further details of the project. If you feel you are able to give some of your time to help with this research, I would be grateful if you would sign the enclosed consent form and send it to Alison Payne at the Eating Disorders Service at **** Hospital (addressed, prepaid envelope enclosed).

Yours sincerely,

Robert Palmer
Consultant Psychiatrist.

## APPENDIX 9

### Interview schedule

**Introduction**

1) Thank for their participation and narrative (if appropriate)

2) Information about me

   Alison
   Clinical Psychologist in training based at University of Leicester

3) The aim of the interview

   Trying to understand the meaning of dropping out of eating disorder services
   Reassure that dropping out is a common phenomena, therefore important that we consider the patients perspective
   There are no right or wrong answers
   I'll be following up some comments from the narratives and some more general questions
   Show the plan of the interview. Last approx 1 hour
   Check consent for tape recording and inform that a copy can be made and reassure that confidential. Explain that recording so that I don't miss any important info
   Ask for comments/concerns about interview schedule

   *Turn on the tape recorder*

**Warm up**

Information about you, what do you do for a living, in spare time. Where do you live ?(if appropriate). Who with? Where from originally?

Early days of eating disorder

   A little bit about when you first realised that their eating was a problem e.g Age
   How long before contact with the service
   What did you feel concerned about?
   How did you understand your early eating problem?
   Who made decision to refer to EDS?

How did you feel about the referral?
What was the reaction of those around you to the referral?

## Initial Assessment

How did the initial assessments go?
What did you understand about anorexia nervosa before and after assessment?
Thoughts and feelings about changing
Expectations of the treatment of your therapist
What do you feel were the expectations of the therapist?

## Perceptions of the disorder

How did you make sense of your eating disorder?
Did your understanding of the disorder change after the assessment?
How do you think the professionals at the EDS viewed your problem?
Were yours and their understanding similar?
How were they similar?
How did they differ?

## Treatment

What did they expect treatment to be like?
When did you begin treatment?
Was the timing ok?
What did your treatment consist of? How long/frequent?
Was this what was expected?
What were your general thoughts and feelings of the treatment?
What was helpful?
What was unhelpful?
What was the reaction to those around you regarding the treatment?
What impact did the treatment have on you?
In your family/relationships
In your work
In your leisure

## Dropping out

Tell me a little about how you dropped out of the EDS e.g negotiated, conscious decision, gradual?
When did you make the decision not to return?
How long did it take to come to the decision?
How did you feel about not attending? What did it feel like when you stopped going?
What were the issues that affected your decision not to return?

Were they related to the treatment .
              The therapist
              Specific to you
              The timing of treatment
What was the reaction of others around you?
What do you imagine might have happened if you stayed in?
What were your hopes and fears?

## Improvements and Unmet needs

What could have been done to improve the likelihood of you staying the course?
What has been left unmet?
What were the good things about treatment (if any)?

## The present

Has anything changed since you left the service?
What has happened since you dropped out of the service?
What were the effects of dropping out? E.g symptoms worse, better
Do you view your disorder differently now? Do you view yourself as different now?
What have been the consequences for you, your eating disorder, your family?
What are your thoughts and feelings on the treatment you received?

## Wind down

Thoughts on narrative and or interview
What happens from here. May receive a letter to explain the general findings.
Ask if they could provide feedback on this letter.

# APPENDIX 10

## Outline of Interview

*This is a rough guide of the topics we may cover. Please feel free to discuss any other issues you feel are relevant to this topic.*

1) A few general questions about yourself.
2) The early days of your eating problems.
3) The first contact with professionals.
4) Your understanding of your eating problems / the professionals understanding of your eating problems.
5) The treatment you received – expectations, type of treatment and your thoughts on this.
6) The process of leaving the service.
7) Your thoughts on how treatment could have been improved.
8) How things are for you now.
9) Your thoughts on this project.

# APPENDIX 11

14th April 1999

Dear ****,

**Re: Understanding the experience of treatment for anorexia nervosa; the perspective of patients who drop out of services.**

Hello again! I am writing to you to inform you of the findings from the above study which you kindly participated in last year. First of all, I would like to express my sincere gratitude for all your help in the project and for sharing with me your experiences of treatment for your eating disorder.

I have enclosed a summary of the results for you to read and keep. I have also enclosed a response form and would be extremely grateful if you would take some time to provide feedback on your own thoughts and feelings on the results. The results are based on the analysis so far, and they are still open to change depending upon your feedback.

The response form contains some ideas of issues you might like to think about, but I would also appreciate your comments on any other aspect of the research. If you would prefer to speak to me directly, please let me know a telephone number I can contact you on, so that we can arrange a time convenient for you to provide your feedback.

Please do contact me if you would like to discuss the findings in more detail, or if you have any other general questions about the research.

Once again, many, many thanks for all your efforts,
Very best wishes,


Alison Payne
Clinical psychologist in training.

## Summary of results

**How were the data analysed?**

As you are aware, your experiences were collected in the form of narrative accounts (or stories), and also by interview. All the information collected was entered word for word into a computer and identifying names and details were changed to protect your identity.

Once all the information was entered, I then read and re-read the information to look for similarities and differences in your experiences. From this a number of 'themes' emerged. Themes are collections of information which seem to be referring to similar issues. After closely analysing these themes, I then attempted to bring all the information together to try and find out if there was an overall theme or pattern in the accounts. The results presented here refer to the overall summary of the findings and are not specific to your individual experiences.

**The results**

The overall analysis of the themes seemed to link the experience of the disorder, treatment and drop-out to the issue of 'control'. Throughout the various stages of the disorder there appears to be a sequence of;

a) **Feeling that you have lost control in your life**
b) **Attempting to gain some control back**
c) **Others behaviours or interventions which then result in you feeling that you have lost control again.**

I will try to explain this more clearly in terms of the stages of the disorder.

**1) Onset**

Onset is the very early stage of the eating disorder.

a = The eating disorder was frequently triggered by a stressful event (for example a bereavement, bullying, accident) or situation (family or school) and this resulted in a feeling that life had spiralled out of control.

b = To overcome this there is a need to re-gain some sense of control in life. When other ways of coping do not work, there are limitations in terms of the way control can be re-gained. Taking control of food intake may provide a sense of control. At this stage, it seems that food may not have been used deliberately to re-gain control, and this happened very gradually, without always being totally aware that food was becoming a way of coping with the stress.

c = At the stage of onset, other people reacted very differently to the eating behaviour. For example, in some instances, family and friends were unaware or ignored the onset. For others, people initially commented on the weight loss in a positive way. However, what is common to both of these reactions, is that neither helped to address the root cause of the eating disorder, as restricting food continued as one of the few ways in which control could be regained.

**2) Maintenance stage**

This stage refers to the progression of the eating disorder.

b = What came out very clearly from the accounts was that an eating disorder was very helpful or 'functional' at times. It helped in 'coping' in difficult circumstances. The sense of achievement gained from restricting food sometimes helped in seeing yourself in a different way. For example, when feeling very bad about yourself, it may have helped you to see yourself in a different light, as someone who maybe had a lot of control and self-will, in that you were able to avoid the temptations of food, when others around you

couldn't. It also helped in controlling the rewards and punishments of yourself and others. For example, where people had felt 'punished' or out of control before, now they were able to control this themselves.

It is not surprising, then, that given that it was such an effective coping strategy, that it was very difficult to see the disorder as a 'problem'. Many of you spoke of denying you had anorexia nervosa, or only partially accepting it. I wonder if by accepting anorexia nervosa as a problem, this would mean that you would have to give up a very helpful way of coping.

c = There seems to be a stage in which others no longer see the weight loss as attractive, and it then becomes 'problematic' for others. Therefore, there is a clear difference between how you viewed the disorder (as a helpful coping strategy) and how others view the disorder (as unhelpful).

Because anorexia nervosa has such a clear symptom (i.e. the weight loss), family and friends automatically attempt to change the clearest and most concerning symptom for them which is the weight loss. Therefore they begin to 'nag', force feed, make threatening comments etc., in an attempt to get you to change your behaviour. However, the weight loss is a coping strategy to deal with the initial cause of the disorder, and others attempts to change this then result in;

a = feeling that you have lost control again.

What may happen from here on, is that this cycle of a, b, c, continues, so that when there is a return to feeling out of control (or a), to regain control (b), you become more isolated or begin to conceal your behaviour in order for you to maintain a sense of control.

To maintain a sense of achievement and the 'buzz' experienced from restricting food, there is a need to constantly reduce the intake of food in order to gain a sense of achievement

and control. Therefore, there is also a similar cycle or 'battle' of control with the disorder itself.

## 3) Help seeking

a = Continued reactions to the eating disorder and the battle of control with the disorder itself, seem to result in a loss of control. So, whereas before it had been viewed very positively, it may now be rather problematic.

b = To re-gain control, there may be a need to seek help. At this stage, another way of gaining control was to try other methods of controlling food intake, such as making yourself sick or trying laxatives. However, this seemed to result in an increased sense of feeling out of control.

c = Many of you were encouraged to seek help for the benefit of other people around you, for example to lesson some of their anxieties. However, when entering into treatment there was little motivation to get better for yourself.

## 4) Treatment

In treatment, this cycle of control seems to continue, and results in a continued 'battle', between losing control and efforts to maintain control. For example the approach of treatment was inconsistent with your understanding of the eating disorder. So whereas you may have felt a need to understand what the root cause of the disorder was, the service used techniques like food diaries and weighing which, again, focused on the symptoms of the disorder. Many of you felt that there was little negotiation regarding the goal of treatment and this again made you feel out of control.

The context of treatment, (in terms of being in a hospital), also seemed to affect your sense of control, as being a patient is sometimes associated with feeling weak and fragile, but this was not always the way in which you experienced the disorder.

To exert control at this stage, you may have wanted to hold onto the eating disorder as a security or have started to question whether you really wanted help to overcome the eating disorder.

## 5) Drop-out.

The approach, context and timing of treatment all seem to increase a sense of feeling out of control again as they all challenge your view of the disorder as being a coping strategy. One of the ways in which to gain control is to drop out. Although initially there may have been a sense of relief, in the longer term many of you felt as though you were burdened with the responsibility for your own recovery.

Following drop-out, people varied in the extent of their recovery in terms of weight gain. It appeared that for most, recovery was partial as the thoughts and feelings associated with anorexia nervosa continued. For example, on some days when faced with stressful situations, there may have been a return to restricting food as a way of coping.

## Response Form

**Name:**

I would greatly appreciate it if you could look at the following aspects of the results and comment on how they compare with your own experiences. For example, did the finding of 'loss of control' fit with your experience of the onset of your disorder?

- The onset of your eating disorder (see point 1 of results)

- Your experience of anorexia nervosa (see point 2 of results)

- Your experience of seeking help (see point 3 of results)

- Your experience of treatment for your eating disorder (see point 4 of results)


- Your experience of dropping out of services (see point 5 of results)


Please feel free to use this space for any other comments about the research or findings.

# APPENDIX 12

**Present:** Claire, Wendy, Alison, Kate, Richard, Emma.
**Apologies:** Anna

## 1. Dates for future meetings:

11th Novemeber     – Wendy minutes
25th November     – Kate minutes
9th December     – Alison minutes
16th December     – Richard minutes

As a rule, meetings to be held fortnightly during Wednesday lunch-times (1.00-1.50 p.m.)
This will be reviewed at the end of term and further meetings arranged.

**Venue:** Wherever the lecture is being held that i.e. this term room AC 10.

## 2. Booking of cassette recorders and transcribers:
Claire to arrange with Sandra a system for booking out equipment to ensure that everyone has access to machines etc. An alternative suggestion is that people pair up and share transcribers. Additional equipment is available from A.V.S.

## 3. Topics suggested for discussion in future meetings:
1. Epistemological positions
2. Coding. People may wish to pair up with someone at a similar stage to them in order to share coding. It was felt that a discussion of 'higher level' coding would be useful. Alison to bring an extract from her narratives to a future meeting to enable practice of coding within the group.

2. Exploration and discussion of past PhDs
3. Sharing of references *
4. Sharing of ideas around interview schedules *
5. Respondent validation

* **Please bring to 11th November meeting**

## APPENDIX 13

This section illustrates an example of open coding. The codes (on the right hand side) show the folder in which the section was placed, and the categories within it.

## NARRATIVE 4:

| | |
|---|---|
| 1  I can't remember exactly when my eating problems started as I have always | ONSET |
| 2  been fairly concerned about my diet and have always tried to eat healthily. | |
| 3  However, I started to stop eating for long periods after my GCSE's in | |
| 4  1993. Over the next two years my weight fell from 10 to 7 and a half | concealment |
| 5  stone. I got away with not eating for a long time as I became vegetarian | of onset |
| 6  and convinced myself that I had many allergies to wheat etc. This way I | |
| 7  avoided eating family meals. | |

| | |
|---|---|
| 8  My mum never said much to me when I didn't eat, but to be truthful I had | concealment |
| 9  become very deceitful and lied about my food intake. One of her friends | |
| 10  who hadn't seen me for ages told her she thought I was anorexic, but my | Reaction of |
| 11  mum said she had tried to deny it as she thought making a fuss would make | others |
| 12  things worse. | |

| | |
|---|---|
| 13  It was Christmas 1995 that I admitted I had a problem, as I was terrified of | MAINTENANCE |
| 14  having to eat with the family. I hadn't kept anything down for weeks, | |
| 15  eating a raisin would put me in a state of panic and I'd have to throw up. | Public admission |
| 16  At one point even drinks. I was weighing myself ten times a day and just | Losing control |
| 17  couldn't go on. | |

183

18  My mum contacted my GP who sent a nurse to see me. I told her that I    HELP SEEKING

19  thought I'd got bulimia as I was making myself sick. She said she thought    coercion

20  I was clinically depressed and suffering from anorexia as I wasn't bingeing    Labelling problem

21  and barely ate anything. I was put on Prozac and referred to the Eating

22  Disorders Unit in January 1996. Prozac initially helped me put on a little    concealment

23  weight and helped me to get on with things and I was able to convince    isolation

24  people that I was better. I was still extremely deceitful and secretive about

25  my eating.


26  I was very reluctant to go when my appointment came through in the    TREATMENT

27  summer later that year, as the majority of time I still didn't admit that I had    meaning of recovery

28  a problem. I had put on weight and thought I was much too fat to have an    ambivalence

29  eating disorder and I thought the people would think I was wasting their    admission vs

30  time. However, persuaded by my mum I went to my initial appointment.    acceptance

31  Having waited this long it was frustrating to be told that if you did need    Not fitting image

32  treatment you would yet again join a long waiting list. He asked me if I    coercion

33  was ready for treatment, as it could be a long hard battle.


34  Half of me was crying out for people to help me, the other half of me    ambivalence

35  wanted people to leave me alone. I think I agreed to have treatment at that    coercion

36  point mainly for my family. I felt terribly guilty that my mum in particular

37  was so worried about me. He suggested that, as there was such a long wait

38  I could see an occupational therapist in the interim period to keep me

39  going. I went to see her first at my doctors surgery and then at ****

40  hospital. She didn't comment much on my eating disorder but focussed on

41  my depression, which at that point was particularly bad, even though I was

42  on Prozac.


43  She suggested that I should defer university for the year and use the time    meaning of

44  out to get well. At that stage I couldn't see what getting better really meant    recovery

184

45  to me. I was ok provided I could still do everything and I pushed myself          MAINTENANCE

46  constantly. While I was studying for my A'levels I would go swimming              Positive effects

47  every lunchtime and work for six hours waitressing every night. At that

48  stage I wasn't sleeping well and as I wasn't eating I don't know how I

49  coped. I just seemed to get some kind of buzz and was constantly

50  hyperactive.


51  Nothing about my eating disorder seemed to scare me, even when I kept            Unproblematic

52  fainting and my periods stopped. I was constantly freezing and couldn't          focusing life around

53  sleep. I couldn't lie in the bath because my bones stuck out, but all that       anorexia nervosa

54  seemed to matter was weighing less everyday. It didn't help that my best

55  friend was also anorexic because rather than trying to help each other, it

56  was like a competition to see who could eat less. The only thing that really     Others reaction

57  upset me was seeing how much I was hurting my mum. I was desperate to

58  escape the constant nagging and my parents were hopeful that university

59  was just the thing I needed.


60  After starting at [University] my eating continued to get worse. Up until        HELP SEEKING

61  that point I was really just not eating and occasionally vomiting what little I

62  ate. I gradually became bulimic and lost more weight. On visiting the            Bulimia -> lost control

63  doctor about a sore throat she commented how thin I was and after               covert help seeking

64  weighing me she said she thought I had anorexia and referred me to a

65  psychiatrist at Uni. She explained to me that it was hard enough starting

66  Uni. Without having an eating disorder and as they had very little facilities

67  in ****, she thought I should go home and receive treatment. The               Situational impact

68  psychiatrist said the same and upped my Prozac dose. I was very aware

69  that my parents didn't want me at home as they thought I put stress on the

70  family.

71  I became increasingly depressed and isolated as people began to realise I     Isolation
72  wasn't eating. I had typically also taken on 3 part time jobs and just wore
73  myself out. I dropped out of Uni. At Christmas and was referred back to
74  the waiting list at the Eating Disorders Unit.

75  I tried to eat at home, but it was extremely hard. I became deceitful, as I     Isolation
76  was sick of people worrying about me. It was clear looking back that I still     Reactions
77  wasn't able to accept help and seeing how desperate my mum was made it     Lack of
78  worse.  She even took me to see a Christian heeler, but even for her I     motivation
79  couldn't get well.

80  In the beginning of January I got myself a job as a live in nanny in London.     Isolation
81  Here I had isolated myself from my family and friends, and in one way I
82  wanted a fresh start, but I think that I thought I was away from all the
83  nagging. However I was terribly lonely and I was being sick up to ten
84  times a day. I only allowed myself to eat apples.

85  In March 1997 I met my husband and he really helped me to learn how to     Positive effects
86  eat properly again. He was interested in cooking, but didn't make an issue     of not focusing
87  of what I ate or didn't.  However, I still only continued to eat in his     on food
88  presence, which although was a vast improvement, wasn't sustainable. On
89  my own I continued to starve, binge and vomit in secret.  From the
90  beginning I was aware that I had been anorexic, but didn't know the full
91  extent until much later.

92  In September 1997 things were not much better although I had put on     Situational
93  weight and was around eight stone. I started a Psychology degree in ****     impact
94  which meant living away from [my husband] in my own flat. I became
95  increasingly depressed and despondent and my confidence was rock
96  bottom. I wasn't eating again, smoking heavily and drinking vodka to help

97   me sleep. It was about this time that my appointment came through. I can

98   still remember when my mum came to visit me. I started crying as I           *challenge to coping strategy*

99   realised I couldn't cope anymore and had had enough. My mum promised

100  me that this time I would get better and she persuaded me to go for my

101  appointment at the Eating Disorder Service. She and [my husband] were

102  behind me 100%. I still however wasn't fully committed to getting better.      *Ambivalence*

103  May be 60% of me did, but I still couldn't see any future without my eating

104  disorder.    It had been my way of coping since Christmas 93.  My mum        *uncertainty of life*

105  took me for my appointment. I was very apprehensive but I did feel I was     *without coping*

106  breaking down and wanted help.                                                *strategy*


107  The nurse was kind to me and said she thought I was very depressed and       *TREATMENT*

108  suggested that I should go on Prozac which I had stopped taking in January

109  that year. She asked me if I would consider leaving University and going

110  into hospital to give myself a real chance. However, on weighing me she

111  decided I didn't need inpatient treatment, but agreed to see me twice a      *Situational*

112  week initially on Fridays and Mondays, which meant staying at home every     *impact*

113  weekend. This in itself caused problems as my eating was always much

114  worse at home and I felt like I just got criticised all the time.


115  I was weighed once a week and she asked me to keep a food diary. This        *focus on symptoms*

116  however, made me much more conscious about what I ate and seemed to          *reinforcing focus*

117  compound the problem. I still didn't admit to my bulimia, even to the        *on food*

118  counsellor. May be I felt this way because it made me confront the

119  problem in black and white and I wasn't able to accept it. I think going on

120  Prozac was the wrong move as it made me not care as much and think I

121  could cope. It lulled me into a false sense of security. I initially felt

122  stronger and yet again thought I could cope. I didn't find the counselling

123  any help because I didn't get any feedback and I thought I should be doing

124  something to get better, yet didn't know what. I found it very frustrating

125 not to be given any suggestions yet I suppose I was meant to be doing that.

126 I found it depressing talking about the past and at the time felt very

127 insecure. There were awkward silences in our meetings and I wasn't sure

128 what to say. I think looking back it scared me as she thought it would take

129 me a year to get better and I'd have to put on a stone and a half. Looking

130 back I realise that it feels much worse initially as you have to cope with

131 your problems and not hide behind the eating disorder, it is a big change

132 after using it after five years. It was the only thing I felt like I could control

133 and still wasn't ready to give it up. I didn't see out meetings going

134 anywhere and I was convinced I could do it on my own. Looking back I

135 really regret not giving myself the chance to get better, but realise it wasn't

136 the right time for me, but I feel annoyed as I might never get the chance

137 again. Nothing that anyone said would have changed my mind as I

138 couldn't change or try and change the way I thought about things and you

139 have to want to do it for yourself.

*DROP-OUT* — *contemplation of giving up control*

*Timing importance of self motivation*

140 I stayed on Prozac and my bulimia stopped. I felt much better about myself

141 and was able to eat two to three meals a day, although I was still very

142 careful about what I ate. I put on weight and my periods started again. I

143 was pleased that I could eat and still be size 8/10. In the middle of

144 December I became pregnant, it was unplanned but I was really happy and

145 hoped that it would be what I needed To make a full recovery. I

146 immediately came off Prozac. My eating disorder was still there but had

147 been kind of hidden by Prozac.

*LIFE AFTER DROP-OUT*

148 During the whole of my pregnancy I felt extremely sick. Being used to

149 making myself sick it was easy just to vomit whatever I ate and my bulimia

150 became much worse. I was under a lot of pressure. I had exams in June,

151 and my wedding and the imminent immigration to ****. At the beginning

152 of July at seven and a half months pregnant, I had only put on two pounds

*continued use of eating disorder to cope with stress*

153    since becoming pregnant. My midwife became concerned and queried me

154    about my eating. I explained that I was constantly sick and I wasn't sure if

155    it was my pregnancy or my previous eating disorder. I was terrified about

156    harming the baby. She referred me straight away to a family therapist at

157    the psychiatric unit in ****. My appointment came through in a week for

158    me and my husband to attend. The night before our first meeting I decided

159    to get better, I needed to be totally honest with my husband about my

160    bulimia, admitting that I made myself sick up to 30 times a day. He was

161    shocked and hurt that I had let it go on for so long without being able to tell

162    him about it.


163    The family therapist helped tremendously, but I think I went into it with a    *Enhanced*

164    much more positive attitude because I knew that there was someone else    *motivation*

165    life at risk and it helped me make the first step. Once I realised I had to get

166    better for me, she gave me lots of constructive feedback on various issues

167    and gave my husband thoughts on how to deal with my eating disorder.    *wider context*

168    This was very helpful and [my husband] has been so supportive. I think    *of treatment*

169    family therapy was effective because it is the people live with who are the

170    most important and need help and understanding. There is no point getting

171    help if the people around you are naïve to your problems and don't know

172    how to deal with it. For us, it looked at the deeper issue of control in our    *Addressing*

173    relationship, and she showed us how we could get through it together. You    *control in treatment*

174    have to learn to be happy and comfortable in your environment. We only

175    saw the therapist four or five times but it started the ball rolling. My eating

176    became much better, the bulimia virtually stopped although the nausea and

177    vomiting continued to a much lesser degree. I had my son in September,

178    which I was thrilled about. He weighed 8lbs 6ozs. Within two weeks I

179    was 9 stone and was able to eat normally, it didn't seem important.

180   My husband then moved out to **** and I moved home. During the last   Situational

181   month my eating has become a problem again, especially as I'm breast-   impact

182   feeding, so I can't go back on Prozac. I'm vomiting and my weight is now   continued use

183   eight and a half stone. I know I'll be better with my husband, but I feel   of anorexia

184   extremely upset that I can't cope on my own and guilty that I can't do it for   nervosa in

185   my son. I really wish that I could continue therapy but at the moment it   stressful times

186   isn't possible. However, I'm hopeful that one day I will be better as I do

187   truly want to be better, but after six years of thinking this way it's hard to   Need for support

188   change and I now realise I can't do it on my own.

**APPENDIX 14**

**Feedback from Participants**

- The onset of your eating disorder

**Participant 1**

a) The feeling of losing control was apparent at this stage, although it is hard to pinpoint any specific life event that may have caused this.

b) I didn't have a strong urge to regain control, although in hindsight food was a way of doing this.

c) Yes, I strongly agree that people do not initially address the root cause for the problem. Although at this stage I didn't see it as a problem.

**Participant 2**

Everything is exactly right – a bit spooky really.

**Participant 3**

Your findings are very similar to my experience, but also with me being at a dance college I was under pressure to keep my weight down to look good in leotards. With everyone saying how good I looked when I lost weight I just kept on losing it. The more I lost the more people would encourage me. Also I was on my own as I lived away from my parents, so in a way losing the weight was a way of keeping control of my life. College was very lonely, and being on your own you had to look after yourself.

**Participant 5**

I agree with what you said. I suppose I did feel out of control even though I thought I was in control.

**Participant 8**

a) I think my eating disorder was triggered by my failure of science A' levels. I had always wanted to do medicine and realised that my low grades made this impossible. I had always been academic and felt let down that the one thing I wanted to do became unachievable.

b) Food was always a big issue in the family and by concentrating on eating I could avoid facing what I was really worried about. I felt like I was achieving something when I lost weight or was able to eat less than other people.

c) My mum ignored my weight loss, thinking that if she made an issue it would make it worse. I took it as thinking that she wasn't really that bothered, or may be I wasn't thin enough.

- Your experience of anorexia nervosa

**Participant 1**

b) Did see it as an achievement for restricting food and losing weight. Agree that by accepting it as a 'problem' it is hard to see it as helpful.

c) Because of other people's concern there is a feeling of selfishness, but at the same time a desire to continue losing weight, a need to conceal illness from others to reduce others concern.

**Participant 2**

This is also completely correct

**Participant 3**

My experience of anorexia is exactly as you found. Even now I feel I haven't got control of it. I put weight on, feel guilty and then go back to square 1. I would never admit to having a problem.

**Participant 5**

I feel what you wrote applied to me when I am ill and it still does sometimes now as well. I felt bad about myself and still do and I thought avoiding food made me a nicer person. It gave me a sense of achievement and a purpose to life.

**Participant 8**

b) It did help me cope because I concentrated on losing weight, which became the goal. Every minute was taken up with calories, food, how to avoid eating, etc. I didn't have to think about the future or problems I was facing. It gave me a buzz to see the numbers on the scales go lower and I felt good the less I ate. I never felt 'thin enough' to have an eating disorder. If I tried to forget about food then I found it hard to cope with life.

c) My mum would nag me to eat which did make me feel like I had no control over anything. If I ate I felt unhappy and yet I was constantly aware of how I was hurting other people if I didn't eat. It was a no win situation.

a) For years I went through a cycle of eating again, then restricted, then getting nagged, then eating and being deceitful (i.e. making myself sick).

• Your experience of seeking help

**Participant 1**

a) Yes, agree

b) I used vomiting and laxatives after I dropped out of treatment, but it did result in feeling out of control.

c) Yes, strongly agree.

**Participant 2**

B and c are very relevant to me

**Participant 3**

It wasn't me who wanted help, it was people around me who were worried. I would never admit to having a problem, even now I never would. I can remember not really wanting to go and being really ignorant to the person who was treating me.

**Participant 5**

Everything you wrote I agreed with. I felt I went into hospitals to lesson people's anxieties around me and I kept wanting to gain control.

**Participant 8**

a) I began to feel I couldn't cope and knew that I couldn't control my eating. Sometimes I wanted to get better, but at other times I thought I could cope on my own and denied my problem.

b) When everyone knew about my eating disorder I felt much more pressure to eat, so was sick more and became bulimic. This felt much worse because I felt like I would lose control over my body and had to gain control by being sick. But then I would feel so ashamed about losing control in the first place. I felt much stronger when I was able to restrict my eating.

c) My mum organised the treatment and I accepted because she was so worried about me. I wasn't prepared to change 100%. I just wanted to make people less worried about me. I did want to change my eating habits, but didn't want to let go fully.

- Your experience of treatment for your eating disorder

**Participant 1**

Yes, total concentration on symptoms rather than cause. Weighing especially makes you feel out of control. Questioning whether you want to receive treatment at all leads to drop-out.

**Participant 2**

All very true, but I feel that not enough is said about how unrealistic it is to ask me to put on so much weight like that. It just stressed me out too much.

**Participant 3**

I really didn't want treatment because I felt good. I looked OK, I didn't want to put weight on. I didn't really want any treatment. I remember to agreeing to try and eat as the doctor wanted me to, but thinking to myself I'm not doing that, I'm OK as I am. Treatment wasn't helpful to me because I didn't want it.

**Participant 5**

I felt I could relate to what was being said. I felt by being in hospital I wasn't getting to the root of my problems. I felt out of control.

**Participant 8**

Your comments on food diaries and weighing were absolutely right. I felt it focused too much on the symptoms. I knew that I could eat better if I understood what made me feel like I didn't have control. I didn't find any benefit from talking about food, because I couldn't work out the cause. But more importantly because I didn't know how to change. I think I felt frustrated because we went over issues with food and I don't know how it was meant to be helping me or what the goal of treatment was other than to put on weight and re-establish normal eating patterns which I had done on my own before, but it hadn't changed anything because I still felt the same way. I felt like I didn't need to be in hospital because I wasn't ill enough or thin enough and there were people that needed help but not me. I wasn't prepared to let control go as I didn't know a better way of coping.

• Your experience of dropping out of services

**Participant 1**

Yes, there is a feeling of responsibility for your own recovery and because you dropped out once you feel awkward for asking for help again.

Symptoms still persist, but I feel that there is no cure and that it stays with you, although you learn to cope with it.

**Participant 2**

I still have that burden of responsibility every time I eat something I shouldn't.

**Participant 3**

I felt better when I dropped out of the treatment. I was pressurised into going in the first place so I suppose I felt in control again. I also didn't want to go to a mental health hospital. I think that if the treatment was part of the hospital I would have carried on going, but just the thought of going to a mental health unit put me off completely. I felt as if I were some kind of psychiatric patient, not a person with an eating disorder.

**Participant 5**

I felt I needed to gain some control back when I dropped out of hospital. I felt I couldn't cope with getting better and putting weight on.

**Participant 8**

The situation regarding treatment was difficult as I had to travel from London every weekend to stay with my parents. I felt they didn't understand what was wrong and just saw my problems in terms of food. I am still much worse when staying with my family. I felt it was making me more obsessed with my eating by keeping a food diary and I wasn't truthful about making myself sick. At the time I was quite happy to continue eating 'safe' foods and I didn't have much intention of getting properly better as I didn't understand what that meant. The environment or timing wasn't right. I think family therapy would have helped had my mum agreed to it. I was relieved when I dropped out. It felt like a weight off my shoulders. I often regret dropping out, but know that it wasn't the right time.

- Any additional comments

**Participant 1**

Alison, I hope this has helped you. Good luck with your research.

**Participant 2**

I'm still struggling to regain the control I felt I had, and currently feel I eat too much food. I guess I'm stuck in a rut, but whilst I have stayed at seven and a half stone or thereabouts I am not prepared to put more weight on, and when I do I take steps to get rid of it as quickly as I can. I try not to weigh myself everyday but I find that difficult too. But I'm still here and living my life, and relatively happy. I wear big clothes to hide it from everyone else, and I don't go out so much.

**Participant 3**

I feel that your findings are almost exact as to what I went through and felt. I still feel now that I'm not in control and found talking to you very helpful. I don't know if it was because I had a male doctor before and I just felt relaxed with you, or because it wasn't as if I was coming for treatment, I was just coming to chat about my experience. If the treatment was more like that, a relaxed atmosphere where you could just talk about what was happening to you and why you were doing it I feel I would have seen the treatment through, whereas before the doctor wasn't really getting to the problem, just really telling me to eat this and that. I was wondering if you were training to help people with eating disorders or if you have now qualified and have patients now, as I felt talking to you very helpful. I still now haven't got over it. I still have ups and downs. I feel now I'm getting older that I am never going to get over it and that I have done some damage to my body. I am over exercising and not eating and taking laxatives again. I feel if I stop taking laxatives I will put on weight. If I don't take control now, will I be doing some damage as regard having a family? If you can help me please get in touch.

**Participant 5**

I found the findings quite helpful as I found I felt exactly like what you put down. The research was good as people can express their own opinions!!

**Participant 8**

I think your results are consistent with how I feel about my eating disorder. I feel that it is very much an issue of control. Ironically of course the eating disorder takes control and you don't have any. I gradually improved my eating and successfully breast fed my baby for 5 months. However, I became increasingly depressed and felt as though I couldn't cope. As soon as I stopped breast feeding I started controlling my food and now I only eat safe foods again; apples, ryvita, salad and vegetables. I have started vomiting again. My weight is 50kg. I don't want people to notice I have lost weight (this is easy as I live in ****), but feel controlling my eating is the only way I can cope.

I feel very stuck here as there is no treatment available and I am determined to get better. I know now that I can't do it on my own, but need to sort out various issues in order to get on with my life. I don't want it to affect my child too. I am prepared to move home to get this problem sorted out but am at a loss as to the best therapy. I was wondering if you could recommend any treatments available in the UK (either private or NHS) and what I would need to do to get on a programme, as I have already dropped out. Could you please contact me with any information as I'm at a loss of what to do. I would be interested to know if there are some types of therapy which you think are more applicable to treating eating disorders and would therefore increase chances of recovery. I would think that therapy would need to differ depending on the individual. Does your research include people who have recovered from eating disorders and how did their view of therapy differ from people that dropped out? Do you think it was just the timing and their approach that was different in treatment or do you think that it was the therapy they received as I believe they use 3 different approaches to therapy at [the eating disorders service]? Anyway, I hope you can read and understand this messy account. Good luck with your research, hope to hear from you.