ADVERSARIAL GROWTH IN YOUNG PEOPLE EXPERIENCING FAMILY ILLNESS

by

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VOLUME I

Submitted for the degree of Doctor of Psychology (Clinical Psychology)

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July 2007

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ACKNOWLEDGEMENTS

I would like to extend my thanks to the people who kindly gave up their time to share their stories for my research — I hope I have done your experiences justice.

I am grateful to my placement supervisors and University tutors for their advice and guidance over the past three years.

Thanks also go to my Case Discussion Group and other fellow trainees, in particular Jen and Elly who have always been there for support and light relief when needed!

Finally huge thanks to my parents, who have supported me all the way, particularly when times were tough. I appreciate everything you have done.
ACADEMIC DOSSIER

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To what extent is membership of an ethnic minority group (in the UK) influential in the process of diagnosis and treatment of psychosis?

Professional Issues Essay
Under the proposed reforms of the mental health act clinical psychologists will be able to assume greater involvement in the processes of 'sectioning' and supervising the treatment of people who are subject to compulsion. What are the advantages and disadvantages of our profession getting involved with these processes? What issues and dilemmas might need to be considered by clinical psychologists as they make a decision about whether or not to accept these responsibilities? How would you decide?

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Adversarial Growth in Young People Experiencing Family Illness.
ACADEMIC DOSSIER

The section comprises of two essays written over the three-year course relating to psychological approaches to stress and professional issues. Also included in this section are three accounts reflecting on problem-based learning tasks undertaken on the programme. Two summaries of the reflective accounts written about participation in the case discussion group during the first two years of training are also presented, and the full case discussion group reflective accounts can be found in full in Volume Two of this portfolio.
APPROACHES TO PSYCHOLOGICAL DISTRESS ESSAY

To What Extent Is Membership Of An Ethnic Minority Group (In UK) Influential In The Process Of Diagnosis And Treatment Of Psychosis?

JANUARY 2005

YEAR 1
1. MENTAL HEALTH AND ETHNICITY

1.1 INTRODUCTION

Discourses surrounding the interface between race, culture, ethnicity and mental health have been apparent in the literature since the eighteenth century (Fernando, 2002). However, in today's society people from ethnic minorities living in the United Kingdom are still receiving services that are both culturally inappropriate and inequitable (National Institute for Mental Health in England (NIMHE), 2004; Patel et al., 2000). This essay aims to explore the ways in which people from ethnic minority groups, with a diagnosis of psychosis, experience the provision of mental health services differently from both the ethnic majority group and from each other. While the focus of the essay will be on the process of diagnosis and treatment, some attention to the content of these issues will be briefly discussed to set the context. This essay therefore seeks to describe what is different, before exploring how and why these differences occur.

1.2 CHOICE OF ESSAY

My choice of essay was mainly based on my learning needs, having never worked with a client from an ethnic minority group or in the field of psychosis and being told this would be unlikely on placement; hence the reflections I present are based on thoughts I have had in the process of writing this essay. However, the choice also predates my preparation for clinical interviews when I struggled with a vignette asking the reader to consider treatment for Mr X, a 48-year-old man presenting with symptoms in line with a diagnosis of psychosis. I dug out textbooks and looked at National Institute of Clinical Excellence (NICE) Guidelines (2002) to learn about the evidence-base, but what had me stumped was the next question: "How would you do it differently if Mr X was from an ethnic minority?". My automatic response was "Of course I wouldn't do anything differently — it would be discriminatory and unethical to provide a different service to a client based on their ethnicity or race".

1 Throughout the essay I have used terms such as 'African-Caribbean', 'Western' and 'people from ethnic minority groups' with some reluctance, since in my mind such terms imply a degree of homogeneity within such 'groups'. This assumption must be challenged, and the reader is asked to bear this in mind.
However, when I reflect upon this way of thinking, it now seems incredibly naïve. Perhaps my own prejudices were evident when I had not considered issues of ethnicity for Mr X when not provided with information about his ethnic origin. Did this mean I automatically assumed he was a White British male? And if so, more importantly, what did this assumption lead me to consider? Did it mean that I only deemed ethnicity as significant factor for people from an ethnic minority group (and hence an ethnic background not shared by myself), or did my cursory answer regard ethnicity as potentially important only if mentioned in the referral?

Perhaps the literature I familiarised myself with about social inequalities shaped my belief that to eradicate inequalities and racism, all people should be offered the same treatments. However, a person’s ethnicity and the connotations of belonging to a minority group are, by definition, important aspects of their experience of the world. Hence to exclude them from consideration would be to collude with institutional racism at simply a different level to providing different treatments based on ethnicity.

1.3 DEFINITIONS

While this essay asks about membership of an ethnic minority group, it does not specify whether it is certain features of the ethnic minority group's culture or the experience of minority status that is key. I have therefore tried to incorporate literature reflecting both of these perspectives. I have applied Fernando's (2002) definition, classifying ethnicity as a sense of belonging or identity with a particular group, which is determined by social pressures or psychological need. This conceptualisation integrates with Owusu-Bempah's (2002) assertion that individuals have multiple ethnicities. My preference for this definition probably reveals my own difficulty in conceptually distinguishing between race, culture and ethnicity, as it specifically clarifies the difference between these concepts, before tackling them interdependently. An important aspect of the essay title relates to belonging to a minority group, which implies that "independent of the basis for that categorisation...one has lower status" (Smolak & Striegel-Moore, 2002, p.117). As such, membership of an ethnic minority group relates to the sense of belonging to a certain group of people, based on varying degrees of comparable cultural
background and racial description, who are perceived as having lower status than the dominant or majority ethnic group (in this essay the White British population). Therefore, aspects of both race and culture may be important in the investigation of ethnic minority group membership.

2. DIAGNOSIS

The process of diagnosis is rooted in the 'medical' model and hence generally considered the domain of psychiatry. Nevertheless, while clinical psychologists emphasise formulation over diagnosis, the processes involved in diagnosis and later assumptions based on the label assigned to the client also play a role in the work of a clinical psychologist. In fact, Fernando (2002) stresses that diagnosis and treatment are often, in practice, difficult to tease apart.

At this juncture, it is particularly tempting to veer into a critique of diagnosis, particularly in relation to schizophrenia (Boyle, 1999). While this is not the aim of the essay, it is an important consideration. If the diagnostic label of schizophrenia is neither valid nor useful for the client, it merely reflects yet another label used to demean, disempower and stigmatise (Hays, 2001).

2.1 CONTENT

According to NIMHE (2004), compared to the majority ethnic group, people belonging to ethnic minority groups are at a higher risk of developing mental health problems. Much of the focus this work has been on schizophrenia, rather than other psychotic disorders, hence this bias is also represented in this essay. For example, numerous studies have displayed how people from ethnic minority groups are significantly more likely to be given a diagnosis of schizophrenia (Bagley, 1971; Bhugra et al., 1997). A prime example is that when compared to young White British men, young African-Caribbean men are ten times more likely to be labelled 'schizophrenic' (Fernando, 2002).
Interestingly, though, this increased incidence among African-Caribbeans defies reports of the incidence of schizophrenia in the Caribbean countries, where rates are comparable to those for the White population in the UK (Bhugra et al., 1996). While the focus of this essay is on the UK, it is noteworthy that in other Westernised countries, similar reports of elevated incidence rates of psychosis for ethnic minority groups have also been found (Zolkowska et al., 2001).

However, differences in diagnosis exist not only between majority and minority groups, but also between different ethnic minority groups themselves. Rack (1982) describes how hallucinations in Asian women are more likely to be judged symptoms of hysteria rather than schizophrenia, while Bagley and Binitie (1970: cited in Littlewood & Lipsedge, 1989) have demonstrated that Irish men with symptoms of alcoholism and schizophrenia were often given a sole diagnosis of alcoholism. It is worthwhile at this juncture to highlight the age of such studies and ponder whether the lack of more recent evidence suggests that such disparities are reducing, or perhaps that such findings unbalance the status quo in this field and hence more research has not been commissioned.

2.2 PROCESS

The effects of ethnic group membership influence the process of diagnosis at very different levels, both practically and conceptually. I have focussed on three different aspects including the reasons why misdiagnosis of people from ethnic minority groups might occur, the cultural validity of diagnostic classification tools and the potential importance of the role of explanatory models of illness in the link between diagnosis and treatment.

2.2.1 Misdiagnosis

According to Fernando (2002) racism within the diagnostic process itself results in high levels of misdiagnosis of people from ethnic minority groups. In order to demonstrate this he discusses the study reported by Loring and Powell (1988) who investigated the diagnosis attributed to written case studies by psychiatrists. The only information changed about the clients in different conditions of the study
related to their gender and race. Both Black and White psychiatrists assigned a
diagnosis of schizophrenia and impressions of dangerousness and suspiciousness
more frequently to the case studies describing a Black client. Although this study
was conducted in America, Fernando (2002) claims that the influence of racism in
the diagnosis of psychotic disorders in Britain is remarkably similar to the United
States. While this study focussed on race, it is possible that it is this aspect of
ethnicity that is particularly important in the diagnostic process for clients from
ethnic minority groups.

It has also been proposed that the misdiagnosis of psychosis occurs in clients
from ethnic minority groups due to a difference in their symptom presentation
(Sharpley et al., 2001). This could be for two reasons. Firstly, it could be that British
psychiatrists unfamiliar with certain beliefs specific to the culture of an ethnic
minority group may misinterpret these beliefs, as Littlewood and Lipsedge (1989,
pp.105) succinctly suggest “perhaps the mental patient does not have a distorted
relationship with reality so much as an inability to present his experiences and
difficulties to the psychiatrist in a form the latter can understand”. Alternatively, it is
possible that members of ethnic minority groups are more likely to have or report
symptoms which are interpreted by British psychiatrists as evidence for
schizophrenia (Sharpley et al., 2001). Within this explanation it is possible that
stigmatisation of hearing voices in Western cultures may reduce the reporting of
such experiences by people from that culture, but not from others (Coleman, 1999).
Then again, clients from ethnic minority groups may express their mental distress in
ways that according to Western notions are more congruent with a diagnosis of
psychosis, but may represent a different experience of that distress. I have personally
found both of these explanations useful in justifying the findings, but particularly the
latter explanation, as it goes some way to explaining the discrepancy between the
elevated incidence of psychosis and the low incidence of depression in Black African-
Caribbeans.

On a very practical level, misdiagnosis can occur through the process of
linguistic misunderstanding. Rack (1982) presents many examples of confusion
between psychiatrists and people from ethnic minorities for whom English is not
their first language. According to Rack psychiatrists have inferred symptoms
including thought disorder and delusions based merely on the mistranslations of
metaphors and regional dialects. Moreover, Marcos et al. (1973: cited in Rack, 1982) reported that Spanish-speaking clients had more symptoms when interviewed in English, partly due to the factors inherent in speaking a different language (e.g. slow speech as a symptom of depression).

2.2.2 Sensitivity Of The DSM-IV

In relation to the hypothesis that some members of ethnic minority groups may demonstrate their mental distress in ways more in line with the Western conceptualisation of psychosis, it seems an appropriate time to discuss the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994). The goal of this manual is to provide a shared understanding of mental syndromes. However, there have been numerous criticisms of such classification systems as they are inescapably representative of Western ideologies (Fernando, 2002). Despite the appointment of a Working Group on Culture and Diagnosis in 1991 whose task it was to advise the DSM-IV Task Force on the importance of culture and ethnicity, not only were many of their recommendations not adopted (Good, 1996), but the recommendations that were pursued did not challenge the ethnocentric assumptions fundamental to the DSM-IV (Kirmayer, 1998). However there has been a new addition to the DSM-IV that summarises the ways in which schizophrenia varies in its presentation, course and outcome across cultures (Hays, 2001). Although this symbolizes a step forward, it does not integrate the significance of ethnicity into the diagnostic process itself. Instead, this addition may even serve to reinforce the notion of people from ethnic minorities as a homogeneous group, different from the Westernised 'norm', rather than as individuals whose personal, intrapersonal, social and environmental situations influence their psychological well-being. Another important adjunct to the DSM-IV has been the inclusion of an 'Outline for Cultural Formulation' (APA, 1994) that emphasises five cultural and ethnic influences to be considered in an assessment. However, again this appears as an appendix at the end of the manual, implicitly diminishing the value of contemplating ethnicity in assessment to an afterthought. Whilst it is clear that steps have been made to encompass issues of race, culture and ethnicity in the diagnostic process, it seems apparent that such steps are not
thorough enough to ensure a culturally responsive diagnosis for people from diverse backgrounds.

2.2.3 Explanatory Illness Models

In her recommendations about making a culturally responsive diagnosis, Hays (2001) stressed the importance of making links between the client's conceptualisation of the problem and the DSM-IV categories. McCabe and Priebe (2004) have found that explanatory models of illness amongst clients diagnosed with psychosis differ according to their ethnicity. In this study, White British clients cited biological factors as causative in their illness more frequently than clients from three second-generation ethnic groups who were more likely to quote social and supernatural causes. While the link between explanatory models and the diagnostic process is not immediately apparent, I wonder whether it is possible that an individual's own explanatory model of illness is a mediating factor in the relationship between the process of their diagnosis and their satisfaction. McCabe and Priebe (2004) found that people who cited biological explanatory models were assessed as having better insight into their condition, were more satisfied with treatment and had better therapeutic relationships. It may therefore be possible that it is the level of congruity between the client's conceptualisation of their distress and the psychiatrist's conceptualisation (which ultimately translates into their diagnosis), which predicts a person's satisfaction with and outcome in treatment.

3. TREATMENT

In researching the influence of minority ethnic group membership on the process of treatment of psychosis, my experience has been that relatively little information exists or is accessible on this matter in comparison to diagnosis (see NIMHE, 2004, pp.41). The majority of information I found in my search related to psychiatric services, which perhaps reflects the options afforded to people from ethnic minorities. While literature surrounding practical aspects of treatment (such as the use of interpreters) is becoming more common, the subtleties of the process of interventions remain rare (NIMHE, 2004). Therefore, this section will attempt to
address the process of engaging in services, developing the therapeutic relationship and the impact of ethnic minority group membership in different models of therapy.

3.1 CONTENT

As with diagnosis, it is clear that membership of a minority ethnic group is influential in the process of treatment of psychological problems, including psychosis. For example, Bhugra et al. (2000) report that African-Caribbean people are over-represented in the proportion of people with a diagnosis of schizophrenia being detained under the Mental Health Act. In fact, belonging to an ethnic minority group more than doubles the chances of being hospitalised during a period of psychological distress (Hatloy, 2002). Once engaged in services, clients from Black and minority ethnic groups are more likely to prescribed drugs and physical treatments such as electroconvulsive therapy (ECT) instead of psychological therapies (Smaje, 1995). Moreover, if they are referred to psychological therapies, Hays (2001) reports that clients from minority ethnic groups are more likely to be seen by inexperienced therapists and terminate their course of treatment earlier.

Satisfaction has consistently been found to be lower in clients from ethnic minority groups and their families (NIMHE, 2004), although, conversely the issue of treatment outcome is a more ambiguous one. It may be the case that outcome for people from ethnic minority groups is “not so much better as different” depending on the way in which outcome is operationally defined (Sharpley et al., 2001, pp.x61).

3.2 PROCESS

3.2.1 Pathways into Care

The pathway into accessing mental health services forms a first impression for an individual and as such must undoubtedly shape clients’ expectations, attitudes towards, and satisfaction with treatment. NIMHE (2004) reports that many barriers operate to dissuade and prevent members of ethnic minority groups from accessing services equitably. Research has demonstrated that for many people from ethnic minorities, the pathway into mental health services is particularly aversive, characterised by low levels of General Practitioner (GP) involvement and high levels
of police involvement and compulsory admissions (Davies et al., 1996). While the lack of involvement of a GP is strongly related to compulsory admissions and use of Section 136 of the Mental Health Act (Cole et al., 1995), perhaps the most pertinent question as to why people from ethnic minority groups do not access support from their GP in the first place seems to be inadequately explored.

3.2.2 Treatment Decisions

After entering services and receiving a diagnosis, treatment decisions need to be made. Littlewood and Lipsedge (1989) report that emotional distress in members of ethnic minority groups is more likely to be seen as somatic by clinicians, hence offering a potential explanation for the bias in choosing more 'physical' treatments for these clients. However, this is not compatible with the idea that White British clients cite biological causes for psychosis (McCabe & Priebe, 2004) more frequently than people from ethnic minority groups, as surely, it should therefore be White clients who receive 'biological' treatments. Or perhaps it is the case that people who cite biological causes are assessed as having greater insight into their condition (McCabe & Priebe, 2004), which is often a pre-requisite for many forms of 'talking therapies'.

Finally, it has also been suggested that people from ethnic minority groups may prefer directive interventions from clinicians adopting an expert role, and therefore treatment decisions are based on client preference (Draguns, 1990). However, Draguns (1990) suggests that instead, the majority of clients, regardless of their ethnicity or status, display such preferences due to the need for help in an unfamiliar and intimidating situation. Drawing on Draguns' (1990) interpretation of this finding provides the therapist with the opportunity to reflect on what they might do to facilitate an environment in which the client does not feel the need for purely directive interventions.

3.2.3 Therapeutic Issues

Research has consistently demonstrated that above all other factors including the therapist's theoretical orientation, the therapeutic relationship established
between the therapist and client is the most significant factor in determining outcome (Bennett, 2003.). Fernando (2002) has suggested that the importance of the therapeutic relationship may be universally valid, although its qualities need to be culture-specific. However, factors associated with ethnic minority group membership may present practical difficulties in forming the therapeutic alliance.

Considering some of the pathways into care clients from ethnic minority groups face, it is understandable that they may form a perception of mental health services as overtly and covertly racist and oppressive (a perception which may in fact be accurate). This will undoubtedly affect their feelings towards engaging in therapy, along with other factors including attitudes to mental health and help-seeking. It is therefore vital that these concerns are openly discussed and overcome before a working therapeutic alliance can be formed (Ravel, 1996).

The concept of empathy as one of the most significant tools in developing a therapeutic relationship transcends all theoretical orientations and according to Draguns (1990) is fundamentally important in bridging gaps in communication. Pinderhughes’ (1995, p.133) definition of cultural competence as the ability to “perceive [culturally different] individuals through their own cultural lens rather than that of the practitioner” is comparable to a somewhat narrower view of my own understanding of the Rogerian definition of empathy. However, it has also been claimed that empathy may be distrusted by people from ethnic minority groups, as it may not travel acceptably across the cultural gulf (Draguns, 1990), leaving this important tool somewhat redundant.

Ravel (1996) has described how language acts as a significant therapeutic tool; hence for clients for whom English is not their first language, this can pose a major barrier to all aspects of engaging in services. The use of interpreters to facilitate communication between the therapist and client (Ravel, 2002) undoubtedly alters the dynamic in therapy and as such affects the development of the therapeutic relationship, although as Ravel (2002) indicates, this effect is not always uniform. While De Zelueta (1990: cited in Ravel, 2002) has described that the assistance of an interpreter allows positive joining with the client and Ravel (1996) emphasises greater scope for reflection and more engagement with the family, the presence of an
interpreter can also make the course of therapy slower and can lead to the therapist feeling more detached from the client (Ravel, 1996).

Given the problems with language and the 'cultural gulf' (Draguns, 1990), it begs the question as to whether clinicians and clients should be matched, where possible, in terms of ethnicity (Tyler, Brome and Williams, 1991). However, the ethnic or cultural discrepancy between clinician and client is not necessarily impossible to overcome (Draguns, 1990), and moreover, elimination of this factor does not ensure culturally competent practice (Owusu-Bempah, 2002). It has even been suggested that while some people from ethnic minority groups may prefer to be seen by professionals of their own ethnicity (Littlewood & Lipsedge, 1989), alternatively an 'in-group' therapist may arouse distrust as a result of perceived incongruity between in-group membership and professional status (Acosta & Sheehan, 1976: cited in Draguns, 1990).

3.2.4 Psychological Models of Therapy

Available literature on the application of psychological models of therapy with people from ethnic minority groups is surprisingly sparse, particularly with reference to a particular disorder such as psychosis. Much of the literature I have located relates specifically to culture and focuses around systemic theory and practice.

Cognitive behaviour therapy (CBT) is the treatment of choice for many psychological problems, and has increasingly been used with people who have schizophrenia (Bennett, 2003). Many of the limited articles available on cognitive behavioural treatments represent those that were used with people from ethnic minority groups, rather than modified or designed to suit their needs (Hays, 2001). In their critique of CBT, Moloney and Kelly (2004) describe how the negative automatic thoughts of White British clients with depression have been observed much less frequently in other minority groups. Using this example, it is therefore possible that clients from ethnic minorities with a diagnosis of psychosis may have a different experience of their symptoms, which may not respond to typical cognitive behavioural techniques. This indicates that therapists need to integrate their
formulation and the use of such techniques into the cultural system of their client (Fernando, 2002).

Tyler, Brome and Williams (1991) state that psychodynamic approaches represent a universalist perspective that determines the framework the therapist enters the therapeutic relationship with. However, this framework may not be applicable to people from diverse backgrounds. Rack (1982) explores how two of the most basic concepts in psychodynamic approaches may be altered when working with clients from ethnic minority groups. He suggests that transference is likely to be difficult to interpret when the client and therapist have very culturally dissimilar backgrounds, as, for example, the role of an Indian father figure may be somewhat different to a British father-figure. Moreover, in psychodynamic approaches, interactions in the therapy session are thought to mirror the exchanges that occur in the client's 'real-life'. Rack (1982) again suggests that this assessment is culture-bound, as for people from different ethnic minority groups, therapy may be an opportunity to trial different ways of interacting in an unfamiliar situation particularly if relationships outside therapy are characterised by social structure and duty. However, I wonder if this represents a criticism with psychodynamic assumptions for all clients, as surely the therapeutic relationship is not identical to all relationships experienced in everyday life by White British clients either.

Instinctively, systemic approaches to therapy would seem the most responsive when considering issues such as ethnic minority group membership, due to their focus on the nature of groups and their sensitivity to difference and diversity. However, historically this would not have always been the case. For example, McGoldrick (1998) emphasises how early structural approaches to family therapy adopted the universalist perspective as a primary lens, accentuating the traditional view of the normative family. Such approaches have been heavily criticised for blaming parents and allowing no role for the consideration of factors such as racism or sexism (Johnstone, 1999). However, applying what Hoffman (1990) terms the lens of a second-order view, it can be seen how the systemic perspective is intrinsic to culturally responsive therapy (Hays, 2001). Hays (2001) states that in order to work with people of diverse identities as therapists we need to be able to critically examine our own culture and ethnicity, our own belief system and values, and our own assumptions. Indeed, it would have been difficult to compose this essay without
adopting a systemic framework to guide and order my thinking and reflections about ethnicity and mental health.

4. CONCLUSION

4.1 SUMMARY

Although for many years it has been clear that people from ethnic minority groups, particularly African-Caribbeans, are more likely to be diagnosed with psychosis, the research investigating why this occurs has received less attention. Existing theories ranged from those that supported scientific racism by suggesting that it was the result of defects relating to the biology of differing race, to those that outwardly challenged such ideologies, by proposing that it was the stereotypes held by covertly racist psychiatrists that led to misdiagnosis (Fernando, 2002). In reality, the picture is far more complex, as practical issues of language barriers interact with more conceptual issues relating to the culture in which assessment tools were developed. Perhaps what is clear in the midst of this picture is that the diagnosis given to an individual and their experience of the process in which it was formed will undoubtedly affect their experience of treatment, an issue that has been subject to far less research. While historically people from ethnic minority groups were less likely to be offered psychological therapies, recent government directives (e.g. NIMHE, 2004) have emphasised that these must become available. It is therefore the duty of psychologists to examine ways in which their practice can be best tailored to the individual needs of clients from diverse backgrounds, although this may raise anxiety levels (Osuwu-Bempah, 2002) or raise issues relating to their own ethnicity that may be uncomfortable.

4.2 HOW THIS ESSAY WILL AFFECT MY PRACTICE

These issues will undoubtedly influence my practice. While due to the remit of the question it may not be reflected entirely, this essay has given me the opportunity to read and think in-depth systemically about the many issues involved in the question. Hoffman's (1990) concept of lenses is one that particularly appeals to me as it offers an alternative method of constructing realities, which could be used to
inform the provision of culturally competent services with any client who is different (i.e. all clients!). The essay has also afforded me the opportunity to start to integrate the scientist and reflective practitioner roles. I have never given my own ethnicity much consideration before. In fact, I have probably adopted the ‘exotic position’ (Halsey & Patel, 2003) and regarded myself to be without an ethnicity. Now, reflecting on my own ethnic background, I subscribe to Owusu-Bempah’s (2002) view that we have multiple ethnicities. I would like to think that I will use my awareness of my own ethnic background and White privilege (McIntosh, 1998) and how this influences me to inform my understanding of the therapeutic relationship, my own defences, belief systems and assumptions in my work with clients.

While the conclusions I have come to in this essay do not reflect ‘the answer’ to providing services that are accessible, sensitive, equitable and effective for people from ethnic minority groups, I wonder that if I do ever find ‘the answer’ it means I have stopped asking the right questions.

4.3 INITIAL INTERVIEW QUESTION

It seems to me, that the initial problem I had lay in separating the concepts of ‘sameness’ versus ‘equality’. The treatments provided to people from ethnic minority groups need not be ‘the same’ as those offered to the ethnic majority, but undoubtedly must be ‘equal’. During the process of writing this essay I came across the label “the ‘colour-blind’ position” to describe my initial response to the ‘Mr X’ interview question (Halsey & Patel, 2003). I wonder to what extent coming across this label mirrors the experience of a client. The initial feeling of relief that the fact a label had been created meant that I must not be the only trainee struggling with these issues, was later replaced by more anxiety, as I read that issues of race, ethnicity and culture often evoke insecurity and anxiety in many qualified practitioners (Owusu-Bempah, 2002). Does this mean there is no ‘cure’ or definitive answer regarding how to not only provide culturally sensitive services, but also how to challenge institutional practices and ideologies that perpetuate the delivery of inequitable services? A feeling of hopelessness descended as I considered how I do not want to be seen as simply another member of a group of people who are thought of negatively by clients. I do not want to be have a racist attitude attributed to me,
just because people may have experienced or expect it from other mental health professionals. However, unlike many clients out there, I have a lot of support in seeking my 'cure'. While there may not be physical treatments available for these issues, I am in a privileged position as I have access to information that I can digest in my own time. As a form of 'talking therapy' I have already taken issues raised for me in the course of writing this essay to supervision. I also have the option of asking clients from ethnic minority groups about their preferences and experiences, which due to the power imbalance may not be mutually reciprocal. Finally, I have my own ready-made support group of people who could be said to share my ethnicity. I certainly feel a sense of belonging to the group of trainee clinical psychologists and while many aspects of culture differ widely between us as individuals, it could be said that we share the culture of the profession. When on a visit to an inpatient ward with another trainee, a client even commented: "You're psychologists aren't you? You can tell – you all look the same".
REFERENCES


PROFESSIONAL ISSUES ESSAY

Under the proposed reforms of the Mental Health Act clinical psychologists will be able to assume greater involvement in the processes of 'sectioning' and supervising the treatment of people who are subject to compulsion. What are the advantages and disadvantages of our profession getting involved with these processes? What issues and dilemmas might need to be considered by clinical psychologists as they make a decision about whether or not to accept these responsibilities? How would you decide?

DECEMBER 2005
YEAR 2
1. INTRODUCTION

The proposal that clinical psychologists could be assigned as clinical supervisors under reforms of the Mental Health Act (Department of Health (DoH), 2000ab; 2002; 2004) has been described as a 'poisoned chalice' (Kinderman, 2003; Newnes, 2004). This essay seeks to explore the 'poison' and the 'chalice' central to the assumption of greater involvement in the process of detention itself and in the treatment of service users under 'section'. Following a brief presentation of a clinical situation that has proved influential in the formation of my opinions about clinical psychologists' involvement in 'sectioning', I will consider both sides to the debate. I will illustrate the arguments presented with reflections on their relationship to the situation with my client, and examine some of the issues and dilemmas facing clinical psychologists, using the Professional Practice Guidelines (Division of Clinical Psychology (DCP), 1995) as a framework for exploration. Finally, I will explore how I feel my clinical experience and other influences have shaped my own views and any consequent desire I would have to be more involved in this process.

1.1 BACKGROUND TO CLINICAL SCENARIO

One of the fundamental ways we come to form opinions is through direct experience and I believe that a situation I experienced on placement has played a key role in determining my opinions and interpretation of arguments related to 'sectioning'. I will briefly outline the situation and later use this to illustrate some of the viewpoints raised throughout the essay.

A client I had been working with, who I will call Sarah, attended her third therapy session immediately following an electro-convulsive therapy (ECT) appointment, which had been scheduled without my knowledge. She had previously discussed her desire for her life to end with myself and her Community Psychiatric Nurse, but in this session, in a slightly confused and dazed state, she disclosed that she had obtained the means to end her life and written letters to her family.

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* I have chosen to write this essay in the first person to demonstrate awareness that I cannot provide an entirely independent view on this subject due to my professional identity, as reflected in the essay title.

* In order to preserve anonymity identifying information has been altered and Sarah is a fictitious name.
talked about my duty of care and she acknowledged that I would have to tell someone. As she was living in a rehabilitation unit I informed Sarah's keyworker, who liaised with her psychiatrist. I was later informed that Sarah had been sectioned and admitted to a local acute inpatient unit where she had previously stayed during a voluntary admission. It was decided that therapy would be inappropriate in such a setting and when Sarah was so distressed and furthermore best that I no longer worked with Sarah, as somebody more qualified would be better suited to deal with a 'complex case'. Sarah proceeded to spend three months in ICU, without any psychology input and began to self-harm severely and frequently (something which had not occurred before). On several occasions when her care was stepped down, she 'absconded' from the hospital and was found and returned to ICU.

2. ADVANTAGES

2.1 DESIGNING APPROPRIATE, SENSITIVE CARE PACKAGES

The literature from survivor accounts and the anti-psychiatry movement demonstrate the atrocities that have been allowed to occur under the rhetoric of 'care' supported by current mental health legislation (Newnes et al., 1999; 2001). By assuming the role of clinical supervisor, clinical psychologists would have the opportunity to put the service user's needs at the heart of the care plan and design sensitive interventions that are respectful, ethical and holistic (Taylor et al., 2003). The introduction of the Mental Health Tribunal (DoH, 2004a) should support this, as care plans will be independently appraised to ensure that they are comprehensive and appropriate for individual service users.

2.2 ELICITING CHANGE FROM WITHIN THE SYSTEM

Newnes (2004) has argued that in its attempt to gain status and respect as a discipline, clinical psychology has assumed the powerful discourses of medicine and psychiatry at the expense of the service user. Mental health services are still dominated by the view of 'mental disorder' as a biological or genetic abnormality internal to the individual (Newnes, 2004; Symonds, 1998). Findings from research
into minority influence in social psychology (e.g. Hollander, 1964) tell us that the way to shift such attitudes is by accumulating 'idiosyncracy credits' within the majority group (by conforming to social norms and expectations before introducing an alternative perspective). Hence entering the system we are trying to change would be an important first step (Hollander, 1964). If we are to truly begin to counter the dominant medical discourse, it will be necessary to get involved in the designing of care packages where we can challenge the routine provision of barbaric and ineffective treatments such as electro-convulsive therapy (Arscott, 1999). In fact, if we refuse to get involved in challenging this practice, surely we are, by omission, colluding with its existence.

Furthermore, Kinderman (2003) describes this new role as an opportunity to centralise psychology's position within mental health services and legislation. So rather than simply contesting the dominant medical discourse, by becoming more involved in the way care is delivered under the Mental Health Act we could provide other professionals and service users with an alternative way of conceptualising mental health.

There have been arguments for the inclusion of a principle of reciprocity (see Joint Committee report, 2005) in the draft Mental Health Bill (DoH, 2004ab). This means that it would be improper to detain people and hence remove their civil rights if services are not adequately resourced for their treatment (Symonds, 1998). Although the Government (DoH, 2005) has resisted this, the fifth condition of the draft Mental Health Bill does state that appropriate services must be available before compulsion can be employed. Psychologists could use this principle in order to fight on behalf of service users for the resources they actually need. Service users have identified a number of resources that would lead to an improvement in their experience, including advocacy, improved communication from professionals and easier access to services (Pilgrim & Hitchman, 1999). These are all discussed in the draft Mental Health Bill (2004), and having a more central role in the processes of applying for section and supervising treatment would allow greater power in campaigning for better resources.
2.3 MULTI-DISCIPLINARY TEAM WORKING

In a different slant on 'getting into the system', perhaps by taking on 'powers of compulsion', we will have the opportunity to reduce some of the barriers between clinical psychologists and other mental health professionals. Taylor et al. (2003) draw attention to the idea that other professionals may have the perception that clinical psychologists "do not want to get their hands dirty". Psychologists within Community Mental Health Teams (CMHTs), for example often refuse to assume the generic roles afforded to other team members, such as 'duty'. The only other profession able to opt-out of such 'crisis' roles are psychiatrists, who themselves are responsible for organising Mental Health Act assessments. By refusing to take on either of these roles, the message received may be that clinical psychology is not suitable for people entering crisis, or simply that as Taylor et al. (2003, pp.35) suggest, we are placing ourselves in a "lofty, unsullied role". Such a role will make it difficult if not impossible for clinical psychologists to form relationships with other professionals and as such be in a position to influence decision-making within teams. Therefore by becoming more involved in the process of sectioning, we would be supporting a generic, community team approach (Turner et al., 1999) and hence reducing the possibility of clinical psychologists within CMHTs becoming an out-group and hence having little bearing in shaping treatment planning and decision-making.

2.4 CAPACITY

The Joint Committee (2005), British Psychological Society (BPS) (2005) and Critical Mental Health (CMHG) (2005) have all been campaigning for the integration of the concept of capacity (or impaired decision-making) into mental health legislation reforms. Hence, compulsory treatment would only be contemplated for individuals who are not deemed to possess the capacity to make an informed decision about their treatment. So far the Government (DoH, 2005) have resisted on grounds that people may be a very high risk to themselves, but still be unimpaired in their decision-making. However, with such strong views from a wide range of sources, it is still unclear whether implementation of a new Bill without reference to capacity will be possible. As clinical psychologists are often asked to carry out capacity assessments, our involvement in the process of sectioning would
facilitate the implementation of thorough assessments, which could ensure people who do not have impaired decision-making are not unlawfully subjected to compulsion.

2.5 SARAH

There is a very real possibility that if Sarah was not admitted for treatment under compulsory powers, she would have been successful in her attempt to take her own life, and hence the Mental Health Act did its duty in protecting her from harm to herself. However, 'treatment' did little to alleviate Sarah's symptoms and instead she became more and more distressed. Although in some services a very different ethos operates to the provision of psychological therapy on inpatient wards, the lack of conviction for the potential role of psychology was apparent in this case. Perhaps becoming approved clinicians or clinical supervisors would centralise the importance of psychology's role in the care of clients facing crisis as Sarah was. I believe that a sensitive care package would not have neglected Sarah's right and desire to work through the overwhelming emotions she faced at the time of being compulsorily detained. Perhaps if a psychologist had taken the role of Sarah's clinical supervisor, they would have had an opportunity to reframe the dismissive attribution of Sarah's self-harm to it being 'behavioural' (i.e. attention-seeking), and therefore staff could have been provided with education about the likely causes of self-injury and implemented strategies that did not involve sedation to help her manage. Furthermore, challenging the use of ECT, which frightened Sarah and had no apparent constructive impact on her symptoms, would have been a role for the clinical supervisor.

3. DISADVANTAGES

3.1 THERAPEUTIC MILIEU

One of the most striking issues facing clinical psychologists assigned to the role of clinical supervisor will be that of maintaining or developing a therapeutic alliance with someone whose rights and liberty they will have effectively removed (Ross, 2003). Holmes (2002) points out that clinical psychologists utilise the therapeutic
relationship as a vehicle for change and that the presence of powers under the Mental Health Act would act as a barrier to the formation of a trusting relationship and the disclosure of certain forms of distress (Hartley, 2001; May et al., 2003). Although Taylor et al. (2003) highlight that when psychologists are most suited to the role of lead therapist, there is no indication that they will be asked to become clinical supervisors, the potential to employ powers of detention in itself could introduce more wariness and suspicion into the relationship between clinical psychologists and their service users regardless of whether the psychologist is trained to take on the role of a clinical supervisor.

In addition, May et al. (2003, pp.182) suggest that the process of sectioning consigns an individual to a “passive child-like role within mental health services”. In what way is positioning people in this role compatible with a psychological approach to treatment espousing collaboration and the ‘expert patient’? Furthermore, instead of collaborating with service users, surely by placing them in this role we would be actively contributing to their levels of psychological distress and hence our involvement would prove anti-therapeutic (Ross, 2003).

Additionally, Hartley (2001) draws attention to the very obvious fact that psychiatric hospital is not a therapeutic environment, which poses the question as to how beneficial psychological interventions are when someone likely to be heavily medicated in a noisy, threatening environment with inadequate resources.

3.2 COLLUSION

There is always the possibility that by entering a system in an attempt to change it, we will find ourselves inadvertently colluding with the system. The observation that “organisations...will, like dragons, eat [a] hero-innovator for breakfast” (Georgiades & Phillimore, 1975, pp.115) remains un-remarked upon in arguments advocating becoming more involved in the process of sectioning. However, recently social psychological research into power and roles has been drawn on as evidence against the line of reasoning that clinical psychologists will automatically act in the most ethical and sensitive way when employing powers of the Mental Health Act (Diamond et al., 2005).
As well as at this explicit level, collusion could occur in a more implicit style. Survivor accounts warn us that sectioning itself contributes to the distress and oppression of people who are already psychologically distressed (Newnes et al., 1999). Hence to become involved in the process we would ultimately be contributing to what may be labelled 'mental health difficulties' or become a perpetuating factor in our own formulations.

Furthermore, detaining someone under media-fuelled mental health legislation that focuses on risk to society, merely serves to reinforce society's view of people with mental health difficulties as 'dangerous'. Despite the Government's (DoH, 2005) hasty denial that this is not the case and some improvement from the original White papers (DoH, 2000a; 2000b) and draft Bill (2002), it is still unquestionably an issue. When this perception in itself is known to contribute to stigma and distress (CMHG, 2005), surely we should be acting to challenge this stereotype rather than promote it.

This is particularly pertinent when under current legislation a hugely disproportionate number of people who are already multiply oppressed by society are forcibly detained (Fernando, 2002). It is possible that the new broad definition of mental disorder will simply exaggerate this discrimination (Holmes, 2002) and as clinical psychologists we therefore need to ask ourselves whether this form of inequitable and stigmatising system is one we want to be implicated in.

3.3 EVIDENCE-BASED PRACTICE

The Government reifies evidence and evidence-based practice (Holmes et al., 2001) yet promotes legislation that defies such principles. For example, risk management has become a priority in legislation leading to an increase in coercive 'care' in psychiatry (Pinfold et al., 2002), yet evidence suggests that our ability to predict and subsequently manage risk is remarkably poor (Crawford, 2000; Otto, 2000). This undue faith in risk assessment coupled with such broad criteria for compulsion will ultimately lead to defensive practice (Marriott et al., 2001), unnecessary detention (Cooke, 2001) and the potential of warehousing of people who are distressed 'just in case' (CMHG, 2005). Despite fervently denying it, in this case
the Government appear to have decided that the widespread media-fuelled stereotype (Parliamentary Office of Science and Technology, 2003) is more compelling than factual evidence.

In addition, Ross (2003) highlights that it has not yet been proved that compulsory treatment is effective and that very few outcome studies exist that examine sectioning as an intervention in itself. As psychologists, drawing on an evidence-base is supposed to be crucial in the justification of our treatment decisions, yet we are now expected to assume a key role in an intervention which is not supported by an evidence-base. Furthermore, studies have demonstrated that predictors of good outcome in therapy include motivation to engage in therapy (Holmes, 2002) and the development of a trusting relationship with the therapist (Pinfold et al., 2002). Again, by assuming powers of compulsion, it could be argued that we would be acting in direct conflict with the evidence-base.

3.4 SARAH

If I had been faced with this issue further on in my career and was asked to become Sarah’s clinical supervisor, it would have had huge implications for the therapeutic relationship, particularly as sectioning itself probably confirmed Sarah’s perceptions of herself as ‘bad’. However, as one of Sarah’s core beliefs was “every time someone finds out who I really am they leave me”, stopping treatment at this point, merely served to confirm her schema entirely. Although Sarah was aware of my duty of care, I do not know if she would have felt able to disclose her thoughts of suicide if she thought I would be able to section her myself. I believe that mental health legislation positioned Sarah, as May et al. (2003) suggest in an entirely childlike role within mental health services, again reinforcing her schemas and undoubtedly contributing to her distress and hopelessness.

Prior to Sarah being sectioned, I was involved in a situation that I now feel deeply ashamed of. However, I have decided to include it in the essay because I feel it is a clear illustration of the notion of collusion. I was invited to a CPA for Sarah after meeting with her twice. My supervisor advised me to provide ‘background support’ rather than actively contributing to the process, and Sarah agreed to this. When I
arrived for the CPA I was informed the purpose of the meeting had been changed and proceeded to observe Sarah’s Consultant Psychiatrist promote ECT as the only feasible treatment option and inform her if she disagreed it did not matter as a second opinion would be sought and Sarah would be required to have it anyway. Sarah’s mother agreed that this might help, so the psychiatrist gave Sarah a hug and left the room. When Sarah’s keyworker asked her how she felt, Sarah just shrugged and then the Senior House Officer closed the meeting. Despite having strong opinions and some basic knowledge of the evidence against ECT, I let Sarah down in that meeting and did not highlight issues of informed consent, the need for more information about potential benefits and side-effects, and that an assessment of Sarah’s capacity would be necessary before she was deemed unable to make the decision for ECT herself. I thought I had felt stifled by the power imbalance in the room with a large number of professionals propounding the medical model of Sarah’s distress. However, when I raised this in supervision, my supervisor informed me that I had done what she would have done in the situation and that maybe ECT was ‘for the best’. I had thought I felt unable to make a stand and support Sarah’s rights due to my inexperience and low status within the team, yet perhaps it was being immersed (as my supervisor also was) in a culture so saturated by the medical discourse that weakened my resolve to defend what I believe in or dissolved my concept of what it is that I believe in.

4. ISSUES AND DILEMMAS

To provide a framework for consideration of the issues facing clinical psychologists as we attempt to reach consensus on our role within the changing mental health legislation, I have decided to use the Professional Practice Guidelines (PPG) (DCP, 1995), which themselves highlight professional dilemmas faced by clinical psychologists. The key points will be highlighted, many of which intertwine with the advantages and disadvantages already discussed.

The introduction to the PPG (DCP, 1995, pp.5) states that “clinical psychologists are committed to providing clinical services that are seen to positively value our clients and which treat them with respect and dignity”. Sectioning, on the
one hand, appears to be the antithesis of treating someone with respect and hence by becoming involved in a process involving the removal of civil liberties we would be directly violating the PPG. However, from a more paternalistic perspective it could also be considered that by becoming involved in this process we are demonstrating our value for clients, by wanting to ensure safety and protection and acting in what we believe to be their best interests.

4.1 COMPETENCE

Paragraph 1.5.1 of the PPG states that as clinical psychologists, we should not persist with treatments that are not proving themselves to be beneficial simply because there are no alternatives. Therefore, the argument that we should become involved in the process of sectioning because it will exist anyway and as clinical psychologists we can make 'the best of a bad job' is not a satisfactory justification.

4.2 PERSONAL CONDUCT

One of the principles of Personal Conduct is to be aware of and monitor power differentials and the potential misuse of power. Sectioning could be seen as the ultimate misuse of power, as a form of social control (Symonds, 1998). This idea is not disputed by some of those currently possessing power under the Mental Health Act, who claim to be proud to be agents of social control (National Institute of Mental Health in England, 2002). If misuse of power is defined as "any infringement of ...personal rights and well-being" (DCP, 1995, pp.9) then the legal process of removing civil rights in combination with the findings of clinically significant post-traumatic stress symptoms following compulsory admission (Morrison et al., 1999) would confirm the view that sectioning is a misuse of power.

Moreover, the PPG highlight that the risk of assuming an abusive role is heightened when power imbalances are coupled with prejudices connected to minority status. It has previously been stated that much evidence exists that people from ethnic minority groups are more likely to be detained under the Mental Health Act (Fernando, 2002). Therefore to become involved in a process which acts to marginalize and further promote social inequalities would surely be unethical and
irresponsible and would merely serve to locate our profession as a perpetuating factor in an individual's distress.

4.3 OBLIGATIONS TO SERVICE USERS AND THE SERVICE

Our duties to service users include the provision of non-stigmatising services (DCP, 1995). With connotations of dangerousness, compulsory detention can hardly be said to meet this standard. In addition, services are meant to "enhance self-efficacy, self-worth and personal dignity" (DCP, 1995, pp.13), which is a stark contrast to the actual enhancement of feelings of unworthiness, humiliation and vulnerability that have been found to occur when being sectioned (Ross, 2003). Rufus May emphasises this point by suggesting that sectioning in itself positions people in a submissive child-like role (May et al., 2003), which is certain to lower dignity and any sense of self-efficacy.

Mason and Jennings (1997) question whom we have a duty to be assisting: the service user, the public or the courts? Although most people's first reaction would be the service user, the PPG (DCP, 1995, 3.1.2.) also explicates our duty to the public. Perhaps then, assuming powers under the Mental Health Act would be a way to exercise this duty, whilst ensuring the sensitive treatment of service users under section.

However, 3.3.5 of the PPG also provides principles for the environments suitable for providing a service. "Accessible, safe, comfortable and clean" (DCP, 1995, pp.15) are not descriptors I have frequently heard applied to inpatient psychiatric hospitals and the therapeutic context of such settings are debatable (Hartley, 2001).

4.4 INFORMED CONSENT

The PPG make our potential role as clinical supervisors feasible by suggesting that "in exceptional circumstances in the public interest" (DCP, 1995, pp.16) consent would not be a necessary requirement to proceed with a psychological intervention. This is consistent with the Draft Mental Health Bill's (DoH, 2004) assertion that although it may be appropriate for clinical psychologists to act as clinical
supervisors, in most cases this duty will be assigned to psychiatrists. However, what is classed 'exceptional' may potentially change over time as further demands are placed on the profession to take on more cases as clinical supervisors, particularly with service users who have been labelled as having a 'personality disorder'.

Furthermore, paragraph 4.4.1 draws us to the point that empowerment can be the most therapeutic tool and hence to disempower a client by removing their opportunity to make a decision about their care would surely be anti-therapeutic and hence destructive. The Government's resistance to include a clause regarding capacity means that it will be difficult for psychologists acting as clinical supervisors to ensure that clients are supported to make decisions they are capable of making (paragraph 4.4.4.2). This is particularly prominent in the issue of advance statements, whereby service users can prepare a plan of how they would like to be treated should they enter crisis. The DoH (2004) have stated that service users will be able to express their views, these views will be read, but ultimately formal powers will override the individual's request. This appears to be completely incongruent with the rhetoric surrounding the 'Expert Patient' espoused by the DoH (1999), but perhaps as clinical supervisors, we can take on the role of supporting service users to make these statements in the first place and then ensure that they are integral to any care plan we design. Moreover, clinical psychologists should also be in a fairly strong position to limit interventions and base them on the individual's goals (paragraph 4.4.4.6).

The PPG state that clinical psychologists should only intervene against an individual's consent after the "gravest consideration" (DCP, 1995, pp.20). This raises the question as to whether psychologists will be afforded the opportunity for grave consideration when pressed for time and pressurised by other team members to make urgent decisions as clinical supervisors (see Ross, 2003).

5. HOW I WOULD DECIDE

As already stated, clinical experience, including that of working with Sarah would undoubtedly affect my decision about future involvement in the delivery of compulsory assessment and treatment. I understand that my limited experience in
adult mental health, in the context of a CMHT will also affect my views and that perhaps if I had worked in a different environment, for example a child and adolescent or forensic setting, I may be approaching this essay with a very different lens. My initial reaction when reflecting on my work with Sarah was that she would not be alive today without the support of mental health legislation to ensure her safety and therefore if this process has to occur, surely as psychologists we should take some of the responsibility to ensure it is done in the most sensitive and respectful way, where abuse does not take place and clients are empowered to make a recovery. However, I am not so sure that is the case. I believe that Sarah's experience of mental health services (I make no attempt to distinguish myself from this process) even prior to sectioning is likely to have contributed hugely to her distress, disempowerment and hence her desire to end her life. I therefore hold that alternatives to mental health services would surely have been the most therapeutic for Sarah.

Articles, papers and books have also been a major contributor to the formation of my decision. Authors who I hold a lot of respect for have, far more eloquently than I ever could, argued against us becoming clinical supervisors, while if I am completely honest I have lost some respect for the shallowness of arguments (including increased status and hence money) proposed by some professionals supporting our adoption of this role.

Pinfold et al. (2002) suggest that informal discussions with colleagues hugely influence our views on a matter. I discussed the essay with another trainee whose views I often share, although am unable to articulate with such conviction. I will admit that I was surprised to discover her opinion was the polar opposite to mine, which prompted me to re-examine my justification for my opinion and reasons for discounting the other decision.

What I am determined will not influence my decision, is the extra money (Double, 2003), status (Double, 2003), prospect of being on-call (Turner et al., 1999) or being sued (Pilgrim & Hewitt, 2001) as I believe if we are seriously considering these as reasons to become involved (or not) in the removal of a person's civil liberties, we have somehow found ourselves in the wrong profession. Symonds (1998, pp.948) cites that the "passions that motivate us to control and dominate
others" are in play in the process of administering mental health legislation, but I also believe that there is a very real danger of this coming into play in our decision-making, as a way of trying to exert power in the mental health system, particularly over our colleagues in psychiatry.

5.1 HOW THIS ESSAY WILL AFFECT MY PRACTICE

I chose this essay, because, if I am honest, it was an area I felt somewhat ambivalent about. However, reading the question made me wonder about Sarah and how she is now. My ambivalence disappeared almost as soon as I started investigating the essay and I now have a strong opinion on the subject. However, talking to my colleague who is writing the essay from an alternative perspective automatically made me think I had misunderstood the arguments somehow and needed to change my opinion. Hence one thing I have learnt is after careful deliberation to make a concerted effort to have conviction in my opinions and then to voice them appropriately. This is applicable to both my academic and my clinical work and I would like to think I will never be in a situation again where I do not voice an opinion if I believe it will benefit the service user.

I will also start to look more critically at my practice and explore in what ways I am currently oppressing clients or colluding with systems without challenge. Again, I am aware that as I am already in the system of 'psychologists' this may be difficult (it is much easier to criticise psychiatry or 'the other' than to critically examine our own work) (Cox & Kelly, 2002). Furthermore, I will consider the impact of psychologists as individuals on the development of policy and the role I, as an individual can have in voicing my opinion.

6. CONCLUSION

I feel that by assuming the powers of clinical supervisor, we would be doing so to further our position of power within mental health services at the expense of the service user: to win an argument about professional dominance between psychiatry and psychology. Instead of hopelessly reflecting on the potential impact clinical
psychologists can have in changing the process of sectioning, we should actively be shifting the focus to what impact we can have on policy and alternative provision. Perhaps our best efforts would be directed into abolishing the use of coercive 'care' and supporting the provision of appropriate and sensitive alternatives. As Janice Hartley eloquently writes "when people refuse psychiatric treatment it is not because they don't want help, but rather they don't want the particular form of help they are being offered" (May et al., 2003).
REFERENCES


PROBLEM-BASED LEARNING

REFLECTIVE ACCOUNT ONE

MARCH 2005

YEAR 1
1. INTRODUCTION

During our first meeting as a case discussion group, on our second day as trainee clinical psychologists, in exasperation one of our group members uttered the words "change is really hard". This utterance provoked more animation in the group than had been apparent in any of the previous 45 minutes of discussion as we grumbled about the ambiguity of the task and being 'thrown in at the deep end' on only our second day. This reflective account seeks to examine the way in which, in light of clinical experience, I now believe that sticking with the concept of change being hard would have been a more challenging, yet potentially more stimulating avenue to explore in the first problem-based learning (PBL) exercise.

2. TACKLING THE TASK

The first couple of meetings as a PBL group were spent discussing the questions that had been prepared for us around the concept of change. I was ascribed the role of chairperson within the group, which felt particularly uncomfortable during the first few days of training, where I considered my own status as distinctly incompatible with the role of chair. Without any real direction to our conversation, probably the most important function of these initial sessions related to building a safe environment in which we all felt able and supported to contribute. As a group, I think this period in which we became quite social-emotion focussed led to a relatively high level of group cohesiveness, where the size of the group allowed active participation from each member.

However, our lack of direction led to a considerable degree of anxiety by the third session and when our tutor guided us in thinking about theory-practice links, we ran with this notion. It gave us a goal, a specified outcome and something we knew was 'logical'. I think it would be fair to say that the anxiety surrounding wanting to succeed in our first assignment, yet being unsure of what was expected of us led us to become very task-focussed.

We each went away and thought about different psychological theories associated with change and how they explained the notion of change being 'hard'.

After discussion of all the theories we had individually presented, for a number of reasons we decided to focus on the transtheoretical stages of change model (Prochaska & DiClemente, 1986). These included the fact that the model resonated with our own experiences, incorporated aspects of other theories and, in hindsight, the fact that it was a relatively simple, uncontroversial model that we felt we all understood to a certain degree was probably a significant contributing factor. Once agreed on this model, I think it would be fair to say that we clung to it for dear life. The notion of change being difficult slipped out of the window as we maintained our awareness on ‘our’ model. We mapped our own and our clients’ experiences onto the model in an attempt to demonstrate the similarity of the process of change despite the contrast in our situations, as such demonstrating our abilities as reflective-practitioners and scientist-practitioners.

On reflection, the degree of resistance we experienced when it was suggested that we change or critique ‘our’ model was significant. This could have been related to the high cohesiveness we experienced as a group, leading to groupthink, where we strived for unanimity of opinion rather than a realistic appraisal of the model. For me, I think a critique may have led to the return to a place where ambiguity and a lack of direction reigned, hence explaining my lack of desire in truly evaluating the model.

3. WHAT I WOULD DO DIFFERENTLY IN LIGHT OF CLINICAL EXPERIENCE

If I was asked to face this task now, four or five months into training, I do not think I would specifically focus on the stages of change model. A key reason for this is that despite the neat compartmentalised view of change that this model offers, in clinical practice nothing appears to be this orderly. I realise this sounds like a particularly naïve reflection, but since starting placement I cannot imagine any client for whom one psychological theory would be sufficient to provide the basis for formulation and treatment planning. Only drawing on one theory would undoubtedly leave something unattended to, and while this offers a not so neat
conceptualisation, I have come to the conclusion pretty quickly that psychological therapy itself is a 'messy' business, where issues do not fall into orderly boxes and single arrows are not sufficient to conceptualise transition for a client.

One of the main reasons I think, we, as a group liked the stages of change model and chose to focus on it specifically was that we felt able to justify this. From a scientific perspective we found an evidence base in support of the model and from a reflective perspective we were able to use the model in helping us to make sense of our own situations as much as those of our clients. Justification is an important aspect of clinical work as being able to defend choices in therapy is essential. However, in retrospect, while we included a critique of the model in our presentation, the resistance I felt about including it was significant. Although I recognised the necessity of a critique of the model I felt so safe in using it I didn't want to consider any evidence against it. From the position of having to justify your work, it seems that it is equally easy to defend your choices as to find contradictory evidence to criticise them, therefore to what extent is anything we do justifiable?

The parallel that my own resistance to critiquing 'our' model offers with clients is considerable. Particularly in my work with clients with eating disorders the notion of 'not wanting to hear' the 'unhelpful' things about certain behaviours or beliefs is often apparent. However, it also highlights another important point, as now I have tried to use the model clinically, most of the evidence I have found actually diminishes its usefulness. When working with clients with bulimia nervosa, it seems the stages of change model is quite apt to describe behaviours that need changing, namely binging and purging. Most clients are aware that these behaviours need changing and many are already in the contemplation/action stages when they start treatment. However, in order to change the pattern of binging and purging, another behaviour (that of dieting or restricting food) also needs to change. In my limited experience, I have found that clients often find this change more difficult. However, without making it, the other behaviours (binging and purging) are likely to be maintained. Treatment for bulimia nervosa based on the cognitive model also involves changing attitudes and beliefs relating to shape and weight, and low self-esteem. The fact that the stages of change model focuses on a single behaviour therefore makes its application in the field of eating disorders very complex.
4. RISK

The notion of justification seems intrinsically related to the concept of risk. As an individual, I am aware of my discomfort with taking risks and I think this intensified to a certain degree with the adoption of the role of chairperson within the group. My perception of this role included a sense of responsibility to other group members and I did not want to jeopardise our first presentation as trainees by choosing an obscure take on the task, which could potentially result in perhaps the biggest risk of all on the course: failure. The fact that the stages of change model was directly related to the PBL title, is grounded in empirical research and highly cited in the psychological literature gave me some sense of security that this approach was appropriate for the task at hand.

I have experienced similar situations on placement where the concept of risk is salient to me. The parallel between working in a cognitive-behavioural way with a client for reasons including its evidence-base and my own sense of security as a practitioner with this approach versus working analytically with a client springs to mind. While the content and process of the latter option may be much richer, it would also be more challenging and the outcome (in my own mind) not as well defined. Being able to tolerate this sense of 'not knowing' represents a change in itself and something I am gradually developing, but particularly at the start of placement represented an enormous risk.

5. CHANGE IS HARD

Numerous ideas about change being hard (or even too hard) have emerged for me throughout my early months as a trainee: the PBL exercise itself and subsequent changes in the way I work and think, my attitude towards failure and the clients' I am working with experiences of change. I think it is accurate to say that the stages of change model simply did not capture this 'hardness'. As in the example above of working with clients with bulimia nervosa, the model just does not allow for the multiple layers of change that need to occur for one observable change to be noted. The time necessary for change to take place also seems to be swallowed by the
model itself, as if information-giving is the only step necessary at the pre-contemplation stage, surely one or perhaps two sessions would be sufficient to move onto contemplation? The reality is nothing like this, and the way in which the model is presented does not seem to allow for debate over the ethical questions it poses for psychologists as to what our role should be for people who do not want to change.

I believe that using the notion that change is hard would have provided us with the opportunity to experience a similar situation to clinical formulation. It would have been necessary to draw on many different theories as appropriate in order to explain the concept, and the theories would have had to be changed over time and fitted to the idea, rather than the idea being pushed and shoved into the model. This would also have demonstrated how over time different theories become more appropriate or significant in ordering our thinking in a similar sense to the process of reformulation.

A potential improvement identified in the feedback we received about our presentation related to the lack of reflection on the PBL process itself. In my opinion the use of the idea of 'change being hard' would have afforded us a prime opportunity for exploring this within the context of both the process of developing and presenting our work. Changing the way I think about presentations and have worked in the environment of PBL has been hard itself. A marked change relates to the notion that members of my group and the presentation audience actually want to hear my opinions and reflections, and in order to present these necessitates confidence in the value of my own contribution. I have been used to being reproached in academic environments for presenting my own opinions without a direct reference to support that view, and this change in stance from a purely scientific to a reflective-scientific practitioner has not proved to be an easy transition.

6. CONCLUSION

In summary, I think as a group we stuck with a relatively safe option for our first PBL task. Anxieties surrounding joining as a group, lack of certainty and the possibility of failure probably led to the decision that choosing a 'riskier' option or one we were less sure of was too hard in itself for this first presentation. However, I
think the themes that were generated through reflection on the process of this task of 'change is hard' and 'learning to be comfortable with not knowing' are ones that will emerge at numerous points throughout training and beyond.
REFERENCES

PROBLEM-BASED LEARNING

REFLECTIVE ACCOUNT TWO

MARCH 2006

YEAR 2
1. INTRODUCTION

Having worked in a service for people with learning disabilities for nearly five months, if I was asked now to tackle to Problem-Based Learning (PBL) task for the first time, I think I would undoubtedly tackle it differently. However, this reflective account seeks to explore why having had the opportunity to think about the PBL task subsequently followed by clinical experience, I would have stayed with the same underpinning philosophy our group initially adopted.

2. TACKLING THE TASK

I think it would be fair to say that our group felt particularly frustrated with this PBL exercise from the outset. As reflected in my last PBL account, we have been aware of taking the 'safe' option and I think we experienced some real ambivalence about, given the limited time, whether to choose a 'safe' presentation that would appease our facilitator and peers or whether to choose an approach that fitted more with and reflected our own beliefs. I wonder whether this reflects the transition into our second year of training, as our professional identities and confidence in our standpoints have begun to develop and we feel more able to voice these. I think this is certainly the case for me, as I am beginning to feel more confident in voicing my opinions in both a clinical and academic context, despite the fact that I am aware people in positions of power may disagree with these opinions. I believe this would be an interesting point to reflect on and could absorb a whole reflective account, but I am aware that it perhaps ties into my reflections on the impact of clinical experience I will draw on later.

After much debate and changed minds about the content of our presentation, we chose to take a social/idealist position (Smail, 2004) in relation to the problem, with the rationale that as clinical psychologists we should not be focussing our conceptualisation of the 'problem' solely on the individual or family system when distal influences in the environment function to disable the individual. We took three distal influences in the environment that we felt were functioning to disable the Stride family: poverty, societal attitudes to people with learning disabilities and the
way services are structured, and explored the impact that these factors might have on a person's ability to parent. We were particularly aware that the system described in the PBL task had been particularly disempowering for Mr and Mrs Stride and felt that part of our role as clinical psychologists is to empower people.

Our facilitator was supportive of our discussions of these issues, but ultimately was very keen to bring us back to a decision about how we would go about a risk assessment. I wonder if she felt frustrated by our apparent lack of consideration of 'practice reality' and held the view that perhaps as trainees we hold unrealistic ideas about changing the world (or at least our client's situations and the way services operate) that will ultimately be disappointed. Although we acknowledged the importance of risk, we thought that the PBL exercise provided us with the opportunity to think a little more broadly and creatively. Smail (1998) makes the point that clinical psychology should be creative and that it is the business ideology adopted by the health service that restricts this creativity and the development of the role of clinical psychologists. I think this is how I felt when our facilitator tried to 'bring us back to reality', as perhaps this is not the reality I wish to be part of. I felt that through doing all of this research into the ways in which people with learning disabilities, and particularly the Stride family, have been disabled by society and then simply describing a risk assessment protocol we would be working against our group ideology.

3. WOULD I DO THINGS DIFFERENTLY IN LIGHT OF CLINICAL EXPERIENCE?

If I was asked to face this task now, five months into my learning disability placement, I think I would have taken a very different approach to the task. I would have undoubtedly had a lot more practical knowledge about the comprehensive risk assessment protocols and the interface between social and health care systems, which would have possibly led me to developing a much more thorough presentation
based on the issues of risk presented in the vignette. However, since being on placement, I have become slightly disenchanted with the role of a clinical psychologist within a service for people with learning disabilities as my experience has been that the majority of work seems to be focussed solely on assessment, often without even meeting the individual. Despite the fact that carefully thought through recommendations are then made in the individual’s best interests, this restricted scope for further work in my service has come as a culture shock to me. On reflection, our facilitator sensitively tried to emphasise this point to us – about how practice reality can limit your remit as a psychologist, but our position as a group was that practice reality should be challenged.

When I first started to consider writing this reflective account, I felt quite despondent about the potential of challenging practice reality and became aware that this may be reflective of the early signs of burnout, particularly due to the other pressures that have been personally challenging for me whilst on placement. This conviction to change things, challenge existing service ideologies and make a difference, leaves us vulnerable to burnout, as according to Georgiades and Phillimore (1975, pp.115) “organisations...will, like dragons, eat [a] hero-innovator for breakfast”.

This is particularly salient, as Isabelle Menzies Lyth (1988) states that belonging to a social system (such as a service) functions as a defence against anxiety. Although this philosophy is often applied to care staff, in my opinion it is equally true of clinicians and qualified professionals. If we actually think about how much we, as part of society and services, are disabling individuals, the anxiety would appear too overwhelming. Lyth (1988) suggested that one of the ways in which she observed nurses to defend against the anxieties of intrinsically anxiety-provoking work was through the attempt to eliminate decisions by ritual task performance. This sounds incredibly familiar if I think back to our initial discussions as a group, where we collected protocols and structured assessments that meant, as a clinician you have as few decisions to make as possible. It also resonates with my clinical experience, as the Trust you are working in decides the protocols and therefore assessments you have to use and the assessment tools often then result in a ready-made decision. Undoubtedly, protocols are essential in assuring consistency and ethical actions, but
in actual fact they "remove ethical considerations from the immediate clinical decision" (West & West, 2001, pp.320).

Lyth (1988) also highlights that a training system that is concentrated on communication of facts and techniques functions as a defence. If I think of what my presentation would have looked like if I had have created it now, facts and techniques would have undeniably constituted the bulk of the presentation. Perhaps it would have been less anxiety-provoking to have stuck with a 'safe' description of the facts of, for example, developmental theory or the way to go about a risk assessment, possibly with a tokenistic reflection of the process at the end.

4. WHAT WOULD I DO?

This leaves me as a clinician with a dilemma — should I just fall in with the service because 'hero-innovators get eaten for breakfast', should I decide never to work in learning disabilities service (although I would be naïve to think that these issues will not be apparent in any other service I work in) or should I fight for my beliefs and risk burnout early in my career? I wonder if perhaps, what helped me most in PBL was expressing my views with my fellow group members and finding that other people shared not only my frustrations, but also my belief that changing systems and services is possible. Kagan and Burton (in press, pp.12) echo this point when they say that change is not only possible but that "alliances united by a shared vision can change and have changed systems".

Furthermore, I think the process that started with the PBL task has led me to consider smaller, more achievable ways of impacting services and the way they affect those people utilising them. I suppose what frustrated me, my group, our facilitator and the audience of our presentation when thinking about these societal issues is 'what do I actually do about it?'. This is echoed in the article on community psychology where the authors (Fleming & Burton, 2001) described trainees wanting 'short-cuts' to practice skills. I can relate entirely to this desire. There have been numerous occasions where I have left workshops or lectures wanting a technique or skill to grab hold of to ease my anxiety about actually sitting in a room with someone who is distressed. However, I think as I am progressing into my career
perhaps I am starting to acknowledge that not every individual I meet is going to want a technique I can teach them to take their distress away, as perhaps that in itself minimises the actual substance of their distress. I realise I am being incredibly over-simplistic, but in my experience what has mattered most to the clients I have had the opportunity to work with is the depth of consideration offered to them and their situation, followed by the design of a tailored package of care from that point.

Therefore, if asked to do the presentation again I would have adopted the same orientation or philosophy underpinning our original presentation. However, in order to provide more of a sense of grounding to the theoretical basis of the presentation, with hindsight I would have drawn on ideas from community psychology, such as the importance of constructional rather than pathological approaches and the creation of new settings as an intervention. For example, I now wonder what belonging to a community would have meant to Mr and Mrs Stride. I also think we very much neglected the children in consideration of the PBL exercise. As the majority of the group were starting placement working with people with learning disabilities and most of our lectures had also focussed on this area I think we were particularly tuned into this field. I wonder how different our presentation would have looked if we were all about to start our child and adolescent placements at the time. However, one of the things I have taken away from my placement experience is the importance of not working in isolation and comprehensively considering the opinions, beliefs and desires of the people surrounding the person who has a learning disability. Therefore, no matter what placement I was about to start, if I was to format the presentation again, I would have paid much greater heed to issues around the children’s development and also the impact of distal environmental influences on the children.

5. CONCLUSION

In summary, I think that despite the time constraints and other pressures at the time of the PBL exercise, the exercise itself provided me with the opportunity to consider issues in a service for people with a learning disability from a perspective which I may not have been afforded if I had solely had placement experience. I
believe that by choosing a slightly riskier option (in terms of the way we might be judged by others) which was more compatible with our group member's beliefs, I found comfort in the fact that other people share my ideas about systems having the potential to change and the importance of our role in not just sitting back, but in making the changes we can ourselves. On reflection, the dovetailing of clinical experience and the PBL exercise has provided a very positive learning experience about practice reality: its advantages, disadvantages, constraints and the extent to which it should be challenged.
REFERENCES


PROBLEM-BASED LEARNING

REFLECTIVE ACCOUNT THREE

FEBRUARY 2007

YEAR 3
When we first received the problem-based learning (PBL) task I have to admit it was considerably low down a very long list of priorities. At the time I was trying to generate a new research proposal and was also starting a new placement. I had spoken to a number of colleagues in different case discussion groups (CDGs) who had already decided to allocate tasks and “jump through the hoop” of PBL in the least painful way possible. At that time this sounded very appealing. When I mentioned it to a fellow member of my CDG I got a reality check “well if they don’t want to get anything from the course then they won’t but we’re going to make it a useful learning experience” she said. I feel ashamed to admit that my heart sank at this point, wondering when I would fit in yet another meaningful learning experience into all of the other demands. As in previous years, we met as a group for a whole day to discuss possible ideas, but I felt as though the discussion took a very different form to our previous structured brainstorming sessions. We talked about things that we disliked about the way the scenario had been presented, we discussed breaking free from the constraints of what has come to be a ‘standard PBL presentation format’ and we talked about our own experiences that seemed to resonate with aspects of the vignette. I think as a group we felt that the vignette had almost become a parody of what it was trying to challenge – by including a number of issues in order to ensure we considered aspects of diversity, I felt as though the scenario made a number of assumptions about issues facing people from different cultural, ethnic, religious and socio-economic backgrounds and therefore perpetuated a number of stereotypes itself.

Thinking about stereotypes around issues of ethnicity, culture and religion led us to generate a number of ideas, such as interviewing people of Muslim faith about their reactions to the vignette. However we felt that this suggested that the issues in the scenario were only applicable to people sharing a similar religious background. Most vehemently we did not want to make assumptions about this family in order to make a ‘neater’ presentation and based on the limited information possibly available from a vignette, we decided we could not base a presentation around Mr Khan as we did not know enough about him as a human being, the dynamics in his family, his cultural background, religious beliefs and life experiences. This led us to consider what we would do if we received a referral letter for Mr Khan containing the only information we had. The answer seemed pretty simple: we would talk to him and
listen. So that is what we decided to do for our PBL presentation. Obviously we
could not talk to Mr Khan, however during our discussions elements of the scenario
resonated with our own memories of friends and family members. The scenario
seemed to encompass a number of factors that shared a commonality throughout
many families: issues around tensions and loyalties. In order to present these ideas
we decided to interview people we knew around the theme ‘tensions and loyalties’
and to film these interviews. We shared a lot of discussion around whether or not to
introduce or conclude our presentation of the interviews and eventually decided it
would be more personally meaningful to allow people to resonate with whichever
part of the presentation they saw fit. We felt it would somehow undermine the
presentation by ‘justifying’ it with an introduction or conclusion.

I was incredibly aware of my own emotions both during and after watching our
presentation on DVD. I felt more anxious than I ever felt standing up and
presenting (and I really do not like standing up to present!) and despite having
watched the DVD a number of times before, I felt very moved whilst watching it. To
say the reactions after our presentation shocked me would be an understatement.
Although I believe it was meant as a joke, to hear someone say we had taken the easy
option by making a DVD infuriated me. I think this reflects my initial desire to “take
the easy option” and not really engage with the process, whereas due to my technical
ineptness burning the film onto DVD alone took me seven hours! Prior to that
several days were spent reflecting on what would make a meaningful presentation,
conducting interviews, discussing how to honour people’s accounts and how this
idea related to our clinical practice and assumptions. I perceived the audience to be
subdued, following our presentation. However, we had one comment about being
“brave”. I think this captured the notion that we felt as though we had somehow
taken a risk by breaking free from what has become a standard PBL presentation
format. Moreover, I think our presentation really reflected our development as a
group across the three years of training and to have other people commenting on
that in itself left us somewhat exposed and vulnerable. Furthermore, these were our
friends or family we had interviewed and who had shared very personal and
powerful accounts with us. I felt incredibly protective of our presentation and when
a colleague applauded another presentation because they said they were going to be
“traditional” I felt quite shocked and hurt that our presentation was being deemed
inferior because it was not "traditional". It was interesting to discuss this in CDG with our facilitator to think through reasons why people might be threatened by something breaking from the norm and this got me thinking about the NHS and how changes as minor as where a notice board should be placed can be discussed in numerous meetings for months and months and still not ever be implemented due to a systemic fear of change. This situation was discussed in a recent article in Clinical Psychology, where the authors cited Menzies-Lyth (1988) work suggesting that routines and 'traditions' offer a decrease in anxiety within a social system, so in order to work in a more creative way clinicians need support in place (Snelling & Wright, 2005). I feel that the support of our group members and facilitator enabled us to be more creative in our presentation.

Writing reflective accounts always stimulates me to think about what I would have done differently if I were to approach the task again. One of the things that bothered me after the reaction from my peers to our presentation and perhaps the similarities between the other presentations was why we had never considered working as a cohort before rather than as individual CDGs. It struck me that it seemed illogical to spend time researching the same information and then present it to other people who already knew that information because they had also researched it. Again it occurred to me that this is incredibly reflective of processes existing in services I am likely to and have previously worked in. In particular I thought about the lack of multidisciplinary working that actually seems to occur in multidisciplinary teams. As I see it multidisciplinary working is an ideal way to share information between different professionals coming at the same topic through different lenses and hence generating a rich view that can engender new ideas. However, my own experience suggests this type of information sharing happens in the NHS to a considerably lesser extent than I would consider beneficial. With hindsight, I thought that surely if we had worked as a cohort on the PBL task and each researched a different area that might have been another way to have capitalised on the learning experience and information generated. I wonder what I could have done to promote this within the context of the PBL presentations. However, when I mentioned this to another member of my CDG she said that there would have been no point as other people did not want to engage in the PBL task. However, I had initially felt this way and still managed with the enthusiasm and
encouragement of others to get the most out of the task, so surely there would have been a way to have worked with other people to have increased the positive connotations with information sharing. I wonder if I was too concerned with the way other people would see me if they thought I was being over-enthusiastic about work. It seems strange that as an adult investing in a professional training course, the associations with what it meant at school to engage in work still seem to be apparent.

Despite the fact that I still feel overwhelmed by my placement and research work I am so glad that I prioritised our PBL exercise as I think engaging with the process has been incredibly beneficial for me. The process has made me so much more aware of how easily I become enmeshed in others' despondency or lack of motivation or enthusiasm and then go on to perpetuate that myself. In fact I can now see how that has happened on placement, a realisation that upsets me, as perhaps due to feeling overwhelmed I have not capitalised on placement learning experiences as much as I could have. I have been incredibly fortunate to be part of a dynamic and motivated group who have helped me have an experience with the PBL exercise that has challenged my apathy and brought it into my consciousness. This experience has therefore heightened my awareness of my potential for burnout in my career, as although I am still very committed to training and the profession I feel as though the increased demands over the past year have heightened my vulnerability to apathy (Lee & Ashforth, 1993). This has made the importance of accessing support in the form of motivated and committed colleagues particularly salient.

On reflection doing a "traditional" PBL presentation would have taught me more concrete information, but I think I have learned more from the process of our presentation. For example, hearing one of the people interviewed got me thinking about assumptions I hold about older people. It seems ironic that our presentation itself was generated from a discussion about stereotypes presented in the scenario, yet the presentation and my current placement both focus on an area in which I am most aware of own prejudice. I know I hold a number of stereotypes in relation to older people, but Shibaji's story challenged some of those assumptions. The way he spoke with hope has encouraged me to start reading around social constructionist approaches to older people. I am not saying the stereotypes I hold in mind have
automatically disappeared overnight, but I am critically appraising them more and noticing them when they affect my thoughts or how I am acting on placement.

Furthermore, I have felt that on my current placement, my work has actually been impacted by the process of PBL. I have felt freer to be more flexible, open and curious in my therapeutic style. However at the same time I perceive that this can sometimes be misinterpreted as reflective of a lack of knowledge, understanding of theory, or technique. Similarly, in writing this reflective account as a narrative instead of extensively linking process to theory, I was concerned that it would suggest to the reader a lack of knowledge about, for example, organisational theories of resistance to change, or models of apathy and burnout. Furthermore it is noteworthy that I perceived our presentation generated some resistance in relation to a focus on process rather than content. However, it is only as I become more confident with what content I do and do not know (or as our CDG facilitator says "knowing what you do not know") I have felt more comfortable with becoming aware of, paying attention to and discussing process issues more and I believe this is reflective of my journey through the past two and a half years of training.
REFERENCES


CASE DISCUSSION GROUP PROCESS

ACCOUNT ONE SUMMARY

SEPTEMBER 2005
YEAR 1
Throughout this account I considered my contribution to the case discussion group and the group's contribution to my own development throughout my first year as a trainee clinical psychologist. I drew on Kolb's (1984) experiential learning theory provide a theoretical framework for reflection on these issues, considering my own learning styles and the compatibility of learning styles with other group members and our facilitator.

The account mapped the process of the group's progression across the year as we moved from a position of being structured and task-focused to embracing reflection and becoming more supportive of each other's needs.

In the second half of the account my reflections shifted to the parallels between my own development on placement and within the case discussion group. Themes discussed related to the process of decision making within the case discussion group and within a multi-disciplinary team; how to incorporate ideas generated from consultancy within the group into clinical work on placement; and professional identity development.
CASE DISCUSSION GROUP PROCESS
ACCOUNT TWO SUMMARY

JULY 2006
YEAR 2
I began this piece of writing by reflecting on the previous year's account and the way I perceived it to mirror my experience of the case discussion group and its facilitation that year. The transition and development of the group was then considered in relation to the problem-based learning exercise in which the group adopted a stance of critical reflection and opted for a potentially more 'risky' approach to the task.

Group process issues such as group cohesiveness and groupthink were explored, and the stance of critical reflection, which the group adopted across the course of the year, was considered. In particular, contextual issues that I perceived contributed to this outlook, such as the position of the facilitator (as separate from the course team) and dissatisfaction with certain practices on placement were discussed. I also used the account to reflect upon the contrasting feedback I have received from the case discussion group and placement on my own personal and professional style.

I concluded the account by demonstrating its reflection on my own development, as throughout the piece of writing I had drawn on many psychological theories and models, but not felt compelled to explicitly name them as in the previous year. Instead I tried to maintain a focus on process, whilst using examples of content illustratively.
CLINICAL DOSSIER

This section comprises of summaries of clinical placement experience gained in the five core placements and advanced competencies placement. Also contained in this section is a summary of the five case reports written for each core placement. The five clinical case reports and record of clinical activity are submitted, in full, in Volume Two of this portfolio.
SUMMARY OF CLINICAL EXPERIENCE
ON PLACEMENT
ADULT MENTAL HEALTH

Client Demographics: Direct work with 11 clients (2 male, 9 female) ranging in age from 18 to 57; psychometric assessments with 3 clients (all male).

Presenting Problems: Anorexia nervosa, bulimia nervosa, depression, psychosis, social anxiety, OCD and personality disorder.

Settings: Specialist Eating Disorders Service, CMHT, Acute Inpatient Ward.

Assessment Procedures: Clinical interviews, questionnaires (BDI, BAI, BHS, Padua Inventory, SEDS, YSQ, ANSOCQ, RMI, FNES), psychometric assessment (WAIS-III, WTAR).

Interventions: Cognitive behaviour therapy, schema-focussed therapy, mindfulness-based cognitive therapy, motivational interviewing.

Other Experiences: focus groups to gather service user feedback; attended locality psychology meetings; presentation to MDT on Readiness and Motivation Interview; attended day workshop on formulation.

PEOPLE WITH LEARNING DISABILITIES

Client Demographics: Direct work with 6 clients (4 male, 2 female) ranging in age from 22 to 61; indirect work with 1 client (female); group work with 7 clients (5 male, 2 female) ranging in age from 25 to 64.

Presenting Problems: Dementia, social phobia/anxiety, depression, behaviour problems and autistic spectrum disorders.

Settings: Community Learning Disabilities Team, residential homes, family homes.
Assessment Procedures: Clinical interviews (HALO, SOAP), questionnaires (STAI), psychometric assessment (WAIS-III, RBMT, TROG-II, Baseline dementia assessment).

Interventions: Cognitive behaviour therapy, mindfulness group.

Other Experiences: co-facilitated dementia training for support workers; attended Health for All Conference; visits included day services, counselling service, residential home, hydrotherapy and music therapy.

CHILD AND FAMILY

Client Demographics: Direct work with 7 clients (2 male, 5 female) ranging in age from 4 to 16; indirect work with 3 clients (2 male, 1 female) ranging in age from 1½ to 8; psychometrics with 3 clients (1 male, 2 female) ranging in age from 4 to 12.

Presenting Problems: Phobias, OCD, self-harm, health anxiety, aggressive non-compliant behaviour, sleeping and feeding difficulties, autistic spectrum disorders, and self-esteem.

Settings: Child and Adolescent Mental Health Service, family homes, school.

Assessment Procedures: Clinical interviews, questionnaires (SDQ, LOI-CV, SDS), psychometric assessment (WPPSI-III, WISC-IV).

Interventions: Cognitive behaviour therapy, narrative therapy, behaviour therapy.

Other Experiences: facilitated teaching session for PRU on Coping with Exam Stress; presentation on Major Research Project to MDT; contributed to service user feedback audit; visits included educational psychology, family therapy, Umbrella service, ADHD clinic, Webster-Stratton Parenting Programme.
OLDER PEOPLE

Client Demographics: Direct work with 4 clients (1 male, 3 female) ranging in age from 62 to 87; psychometrics with 2 clients (1 male, 1 female) ranging in age from 72 to 89.

Presenting Problems: Dementia, atypical depressive episodes, Charles Bonnet Syndrome, bereavement, Parkinson's disease and generalised anxiety.

Settings: Community Mental Health Team for Older People, residential homes, family homes.

Assessment Procedures: Clinical interviews, questionnaires (GDS, HADS), psychometric assessment (WASI, NART, WMS-III, BADS, SRMT).

Interventions: Narrative therapy, cognitive behaviour therapy.

Other Experiences: consultation to staff on a continuing care ward; presentation on Mindfulness Therapy to MDT; attended workshop on Dementia Assessment Tools.

ADVANCED COMPETENCIES

Client Demographics: Direct work with 7 clients (3 male, 4 female) ranging in age from 6 to 17; family therapy reflecting team with 6 families.

Presenting Problems: Compulsive behaviour, anxiety regarding parental separation, phobia, health anxiety, bereavement, violent behaviour, anger, depression, eating difficulties.

Settings: Child and Adolescent Mental Health Service.

Assessment Procedures: Clinical interviews, questionnaires (BYI).

Interventions: Narrative therapy, solution-focused therapy, systemic family therapies.

Other Experiences: attended workshop on community systemic approaches.
ADULT MENTAL HEALTH CASE

REPORT SUMMARY ONE

A Motivational Approach to Working with a 25-year-old Woman with Chronic Anorexia Nervosa

SEPTEMBER 2005

YEAR 1

In order to preserve anonymity for both services and individuals, identifying information and details have been altered through the report and all names used are fictitious.
Reason for Referral

Jessica Aldwich, a 25-year-old white British female was referred to a specialist Eating Disorders Service by her care coordinator at the Community Mental Health Team for anorexia nervosa.

Presenting Problem

The referral stated that Jessica had a history of long-standing mental health problems, including depression, anxiety, phobias, self-harm, and anorexia nervosa dating back 12 years. Jessica restricted her food intake to fruit and yoghurt, or on a bad day fruit juices alone. She took large quantities of laxatives and slimming pills and had a pervasive fear of being fat.

Assessment

A Consultant Psychiatrist conducted Jessica’s initial screening assessment at the Eating Disorders Service with her grandmother and care coordinator present.

Jessica described a difficult childhood, in which she was physically abused by her mother and placed on the at-risk register. Jessica and her mother battled over food: Jessica was made to eat spoiled food days after she initially refused to eat it and on occasions was pinned to the floor, while her mother physically forced food down her throat. Food was also withheld as punishment. Jessica was bullied at school and started dieting and skipping meals aged 14. At age 16 her weight was six stone and she was admitted to an inpatient unit, where she stayed for two years before being discharged to the care of her grandmother, but eating no solid foods.

Jessica completed the Beck Depression Inventory, Beck Anxiety Inventory and Stirling Eating Disorders Scale, scoring in the severe range for each item on every measure.

Formulation

Predisposing factors to Jessica’s eating distress were hypothesised to include the physical abuse and emotional deprivation she faced in childhood, with food being used as punishment. Furthermore, the bullying Jessica faced in relation to her
physical appearance and her mother's preoccupation with dieting might have led to an association between Jessica's low self-esteem and eating.

As is often the case in anorexia nervosa, the development of Jessica's eating disorder followed a period of dieting in early adolescence, at the time of the maturational crisis. At this time in her life, Jessica experienced severe bullying at school and was put into care, hence barriers already existed that made the accomplishment of developmental tasks more challenging.

A number of anxieties seemed to perpetuate Jessica's difficulties in her relationship with food. She experienced an intense anxiety in relation to weight gain, but also anxiety related to becoming independent, meeting and socialising with her peers and having expectations placed on her. Such anxieties led to phobic avoidance, to a degree where Jessica led an exceptionally restricted life. Furthermore, anorexia allowed Jessica to focus on food instead of her past, which served as another example of avoidance. Moreover, when losing weight, Jessica experienced strength and confidence that she had not felt in other areas of her life.

**Intervention**

I was asked to meet with Jessica for motivational work regarding entering the day programme at the Eating Disorders Service. I met with Jessica for a total of six, hour-long sessions once a week, followed by a review appointment.

Literature suggests that the first step in motivational work is assessing the client's position in relation to change, in order to appropriately tailor interventions to the individual. A number of tools were used to explore Jessica's thoughts about change including the Readiness and Motivation Interview for Eating Disorders and the Anorexia Nervosa Stages of Change Questionnaire.

Based on the thorough assessment of Jessica's motivational status, I decided to use strategies based on the specific process of change identified as important in making transitions from one stage of change to the next. In Jessica's case this included re-evaluating the anorexia nervosa, shifting the balance of pros and cons and enhancing self-efficacy. Jessica and I therefore discussed models of change and looked at the pros and cons of having anorexia nervosa, using the Decisional Balance
Questionnaire and a letter-writing exercise. This enabled Jessica to recognise her ambivalence and conflictual feelings about her eating disorder. Using a cognitive model and schema-change techniques we considered Jessica's life goals and their compatibility with anorexia. Furthermore I used Socratic questioning to assist Jessica to draw on her previous experience of change (for example, stopping vomiting) to increase her self-efficacy in developing the skills and abilities she already possessed for future change.

Outcome

At the end of our sessions, Jessica decided that the prospect of facing her phobia of putting on weight and increasing her repertoire of foods in the environment of day care was too frightening. Although this might be taken to suggest the intervention was unsuccessful, Jessica made an active decision that although she needed to change, she did not feel ready at this time, suggesting that she had taken responsibility for decisions related to her eating disorder, which is compatible with the end goal of a motivational stance (to assist the client in deciding what it is that they want to do about their anorexia nervosa). Furthermore, Jessica reported that she had learned a lot about how her eating disorder had developed and acquired a new perspective that she could use in the future to re-evaluate whether she wanted to make changes then.
ADULT MENTAL HEALTH CASE

REPORT SUMMARY TWO

A Cognitive-Behavioural Assessment and Intervention with a 57-year-old Woman with Chronic Depression and Anxiety

MAY 2005

YEAR 1

In order to preserve anonymity for both services and individuals, identifying information and details have been altered through the report and all names used are fictitious.
Reason for Referral

Pamela King, a 57-year-old white British female, was referred to the psychology service within her Community Mental Health Team by her Care Coordinator. A psychological assessment was requested as Pamela was struggling with her anxiety symptoms and seemed "stuck psychologically".

Presenting Problem

Pamela presented with a history of chronic anxiety and depression dating back to age nine. She reported feeling low in mood and described herself as a "constant worrier". She also experienced chronic arthritic pain and frequent migraines. Pamela's daily routine and activities were severely restricted, and she felt frustrated that it took her all day to wash up from breakfast and prepare an evening meal. Her days included no activities she considered pleasurable and she rarely left her home.

Assessment

Pamela attended an outpatient initial assessment, which lasted approximately one hour. Pamela reported that both of her parents had mental health difficulties: her father had a diagnosis of paranoid schizophrenia and she described her mother as neurotic. Pamela reported severe physical and emotional abuse by her parents throughout childhood and she was forced to assume the role of caretaker to her younger siblings and the family home. At this time Pamela began to experience symptoms of depression and anxiety. Pamela was forced to leave school by her parents at age 15 and met her husband Derek two years later. Pamela reported several traumatic life events during her marriage such as the loss of her first child late in pregnancy and a number of bereavements, including the murder of a close relative. In 1983 Pamela was diagnosed with Pre-menstrual Syndrome, which led to her entry into mental health services and cessation of employment. Since this time Pamela experienced a number of health problems including thyroid and hormonal problems, Chronic Fatigue Syndrome, Irritable Bowel Syndrome and arthritis, which led to an increase in her depression and anxiety and a decrease in her perception of her ability to cope with day-to-day tasks. Pamela had experienced therapy with a number of different psychologists across the duration of her
depression. On the Beck Depression Inventory and Beck Anxiety Inventory Pamela scored in the severe range.

**Formulation**

A cognitive-behaviourally informed integrative approach to formulation was adopted as cognitive-behavioural approaches make explicit the link between emotions, cognitions, behaviour and physical symptoms, which seemed particularly pertinent given Pamela's physical health problems.

It was hypothesised that worry and anxiety could be conceptualised as an adaptive response for Pamela as a child in an abusive home environment, as she described how forward thinking and planning led her to avoid violence and hence remain safe. Furthermore, it is possible that the role of caretaker that Pamela adopted as a young child led her to associate achieving household chores with pleasing others. Avoidance is known to perpetuate cycles of both anxiety and depression. Pamela, avoided going out due to a fear that she would develop a migraine and be unable to get home. This meant she never experienced exposure to disconfirming evidence. Furthermore, as the avoidance continued, her anxiety levels heightened and catastrophic thinking amplified the consequences of feeling unwell when not at home. Moreover, it seemed that other thinking distortions were operating in the maintenance of Pamela's distress. It could be suggested that 'failing' to meet the standards she set herself for household chores was interpreted catastrophically due to the consequences such 'failing' would have had during childhood (i.e. physical harm to Pamela). While this was based on prior experience, such rules were perhaps less helpful for Pamela in adult life. Pamela could have been described as having an external locus of control as she experienced life as a chain of negative events happening to her, over which she had no control. This may have contributed to her low self-efficacy and been related to cognitive distortions.

**Intervention**

I met with Pamela for a total of eight, hour-long sessions of cognitive-behaviour therapy over a period of three months. To provide context to the therapy we collaboratively developed a formulation using the cognitive five-factor model of life experiences and Beck's cognitive model of depression. We used discussion of recent
events as a basis for cognitive restructuring. Pamela found it particularly difficult to identify the key thought that was associated with the most emotional charge (or the 'hot' thought) and hence the downward arrow technique was employed. Pamela continued this as homework, and the idea of cognitive distortions particularly resonated with her experiences, so identifying these became a core component to her thought monitoring and challenging.

Pamela graphed her activity and mood to demonstrate the link between affect and pleasurable behaviour. It emerged that Pamela was engaging in a 'boom-bust' pattern of activity, whereby she oscillated between periods of intense activity and rest, hence leading to reduced accomplishment and increased fatigue. Activity scheduling was therefore discussed and planned. I also provided Pamela with some psychoeducation on the principles of goal-setting and we used graded hierarchies (which fitted in with the concept of pacing) to break one of Pamela's long-term goals into smaller more achievable steps. However Pamela found goal-setting difficult to put into action at home.

Outcome

At the end of therapy, Pamela's anxiety symptoms score had reduced to 'mild', whilst her depression symptom score was still 'severe'. Pamela noticed improvements in her ability to reduce her adverse emotional reactions by challenging her thoughts. While initially she was able to decrease the intensity of the emotion (on a scale from 0-100) by approximately 10 points, by our last session this was nearer 40 points. During therapy, Pamela started to increase her activity levels throughout the day, although had difficulty in instigating this in a paced manner. She began shopping and fishing with her husband and started swimming with her support worker.

Reformulation considered systemic issues, such as Pamela's husband's anxiety and the health service's role in the maintenance of Pamela's view of herself as a person with mental health problems.
PEOPLE WITH LEARNING DISABILITIES CASE REPORT

SUMMARY

A Cognitive Assessment with a 27-year-old Man with a Learning Disability to Explore the Possibility of a Diagnosis of Asperger Syndrome.

APRIL 2006
YEAR 2

In order to preserve anonymity for both services and individuals, identifying information and details have been altered through the report and all names used are fictitious. The client has given written consent to this report and the original consent forms are kept in the client's hospital file.
Reason for Referral

Jim Khan was a 27-year-old man. He was referred for a cognitive assessment by his counsellor at the Community Learning Disabilities Team (CLDT). Jim had concerns regarding memory difficulties and requested further information about his learning disability and diagnosis. Jim's counsellor thought Jim might have Asperger Syndrome (AS) and the referral asked for an exploration of this possibility.

Presenting Problem

Jim's main concerns centred around work and relationships. Jim's counsellor reported that Jim had difficulties in dealing with events he believed were unjust (whether these were racist attacks on the news or someone teasing him at work) and would 'explode with anger' usually directed at his mother or sister. Jim also experienced problems with his memory; giving examples of forgetting appointments if he did not write them down and chores his mother asked him to do. Jim perceived that his mother interpreted this as Jim being wilfully difficult. Jim could not remember how long he had experienced problems with his memory for and felt as though the difficulties fluctuated from day-to-day.

Assessment

I met with Jim for a total of four two-hour long sessions and Jim gave his permission for me to meet with his mother for one two-hour long session. A literature review was conducted, exploring the theory of mind, central coherence and executive function theories of autistic spectrum disorders. In line with the current literature and Jim's presenting problems of memory difficulties, managing the demands of social situations, difficulties within his relationships and over-reliance on learned rules, it was hypothesised that he would meet diagnostic criteria for a learning disability and AS.

A number of neuropsychological assessments were chosen to test this hypothesis. As there was no known information about Jim's intellectual abilities, the Wechsler Adult Intelligence Scale (WAIS-III), a test of general intellectual function, was chosen to provide a useful basis for further investigation. The Rivermead Behavioural Memory Test was used to assess Jim's difficulties with everyday
memory tasks. The Test for Reception of Grammar (TROG-2) was chosen to assess comprehension without relying on verbal explanation. The Surrey Oaklands Asperger Procedure consists of the State Trait Anxiety Inventory (STAI) to measure symptoms of anxiety, an informal test of social know how and its uses to reveal idiosyncratic thinking common in people with AS and theory of mind tests assessing first-order and second-level perspective taking. The procedure also included a semi-structured clinical interview based on diagnostic criteria of AS, which was carried out with Jim and his mother separately.

Findings

In comparison with other people of the same age, Jim's Full Scale IQ on the WAIS-III was in the extremely low to borderline range. His Performance IQ was significantly higher than his Verbal IQ. Jim had three weaknesses all falling in the verbal domain, namely Vocabulary, Arithmetic and Comprehension. On the RBMT Jim's standardised profile score indicated that he had poor memory, although this was not inconsistent with research with people with learning disabilities. Jim’s performance was superior for remembering visual stimuli (such as faces and pictures) than for verbal information Analysis of Jim's performance on the TROG-2 indicated a pattern of sporadic errors, which implicated a processing problem.

On the STAI Jim's anxiety levels were greater than have been found in the general population. In his responses to social stories, Jim displayed a strong notion of learned rules, and was particularly concerned with what might be considered rude. Jim demonstrated a level of idiosyncratic thinking.

Jim correctly responded to the first-order theory of mind tests which research has found that 80% of children with autistic spectrum disorders fail. However he struggled more with the level two perspective-taking task.

Discussion

Jim's PIQ was higher than his VIQ, which is the opposite of what is typically described in the neuropsychological profiles of people with AS. Furthermore Jim's profile on the WAIS-III did not correspond to the suggested 'typical' profile of someone with AS on the WAIS-III.
Jim's difficulties with level two perspective-taking on theory of mind tests seemed to be related to his comprehension and memory of the scenario, rather than purely mentalising abilities.

From a central coherence perspective, detail-focussed processing in people with a AS leads to higher scores on Block Design and lower scores on Object Assembly. Consistent with this, Jim's highest score was on Block Design. However, he also performed well on Object Assembly. Whereas people with strong central coherence find that contextual information and narratives aid memory of a story, people with weak central coherence are more likely to remember specific facts at the expense of the gist of the story. On the RMBT Jim did not appear to gain any benefit from the meaning of the story, whilst he did remember some of the specific facts.

Perseverating errors found in people with AS have been associated with the application of learned rules in a rigid manner, which Jim demonstrated in his responses to the social stories and in everyday life situations.

Conclusion

Following clinical interview with Jim and his mother and observations during our sessions, it was evident that he did not meet diagnostic criteria for AS. Jim met criteria for social impairment, speech and language peculiarities and perhaps in repetitive routines. However, he did not experience difficulties in the areas of narrow interest, non-verbal communication and motor clumsiness.

Recommendations

Following Jim's assessment several recommendations were made for his future care. These included: a joint meeting between the professionals involved in Jim's care to discuss his ongoing support needs; an advocate vis-à-vis Jim's concern about his vulnerability to exploitation and desire for advice in managing decision-making; and memory aids. Furthermore, as Jim experienced many difficulties shared by people with a diagnosis of AS, such as struggles in social interaction and rigid thinking about social rules, it was considered that AS might be a useful concept to help the professionals involved in Jim's care to think about the sort of difficulties he experienced and hence how best to support him.
CHILD AND FAMILY

CASE REPORT SUMMARY

An Integrative Narrative and Cognitive-Behavioural Approach with a 7-year-old Boy Facing Difficulties with 'Worry'

SEPTEMBER 2006

YEAR 2

In order to preserve anonymity for both services and individuals, identifying information and details have been altered through the report and all names used are fictitious. The client and his parent have given their consent to this report and the original consent forms are kept in the client's hospital file.
Reason for Referral

Ben Brown, a seven-year-old boy, was referred to his local Child and Adolescent Mental Health Service (CAMHS) by his General Practitioner (GP). The referral suggested that Ben had obsessions and compulsions, with a particular focus on body image problems.

Presenting Problem

Ben described his difficulties as "lots of little worries". Two years previously Ben began to lose confidence in cleaning his bottom after using the toilet, and started to ask his mother for reassurance that he had done it properly. There was no apparent trigger for this loss of confidence and over time Ben began to develop other worries, such as getting a splinter from furniture, wearing his clothes back to front or without the buttons done up straight, touching the DVD player or remote control and his hair, body or breath smelling. On a 'good' day Ben asked for reassurance ten times, whereas on a bad day Mrs Brown reported it was 'tenfold'.

Assessment

I met with Ben, his parents and sister at CAMHS for the initial assessment and one week later met with Ben and Mrs Brown to complete the assessment. The Strengths and Difficulties Questionnaire (SDQ) was completed by Ben's mother. Ben's only scores on the SDQ that fell outside the 'normal' range were the emotional symptoms scale and the total parental impact rating. Ben also completed the Leyton Obsessional Inventory — Child Version (LOI-CV) survey form, and reported 10 out of the 20 obsessions or compulsions measured by the LOI-CV.

Formulation

A narrative approach to formulation was adopted for a number of reasons. Firstly, there appeared to be no obvious triggers to Ben's compulsions and Ben had previously attended cognitive-behavioural sessions, which he did not like. I felt that a narrative approach would be more engaging for Ben and allow him to actively collaborate in the therapeutic process.
'Thin descriptions' are stories about a person that afford little space for the complexities of life and contextual factors to be taken into consideration. For Ben, 'worried', 'embarrassed' and 'distressed' could all be considered 'thin descriptions', as these phrases dominated his family's and GP's account of him, leading to a 'thin conclusion' about Ben as being 'shy' and 'anxious'. It is possible that this 'thin conclusion' about Ben led him to feel disempowered and to privilege the information about himself that supported the problem-saturated story.

It is possible that the dominant problem-saturated story of Ben as a 'worrier' meant that other instances that fitted with this plot were more easily remembered and privileged and therefore the dominant story gained thickness and richness.

**Intervention**

I met with Ben and his mother for seven, hour-long sessions over a period of three months. These sessions were followed by a celebration with Ben and his family.

I attempted to initiate externalising conversations with Ben and Mrs Brown, in order to separate Ben from the problem, to allow space for exploring the effects of Worry on Ben's life, relationships and view of himself. Worry was constructed as "a mischievous little child" who was trying to trick Ben out and it was decided that we would all need to work together to stand up to Worry. I employed a cognitive-behavioural explanation of Worry's 'deviousness' by suggesting that Worry could try and trick Ben out by pretending it will never go away (or habituation to the anxiety response), but that Ben would need to outwit it by practising the things Worry would not like him doing (exposure). We also considered that Worry eats up reassurance, which makes it grow bigger, but that without reassurance (response prevention) Worry would shrink away.

Using the behavioural principles of systematic desensitisation, Ben constructed a Worry ladder. We then thought about goals (or things Ben could do that Worry would not like) starting at the bottom of the ladder and working up. The Worry ladder created opportunities for unique outcomes to emerge.
Ben seemed to particularly pick up on the notion of Strength in standing up to Worry and in order to trace the history of Strength in Ben's life, he created a timeline about times when Strength had been around.

We also used a therapeutic letter-writing campaign, as part of a re-membering practice, in which Ben and I constructed a letter to his family members, asking them to reflect on their observations of his journey with Worry and Strength. The letters were read out in Ben's celebration at the end of therapy and Ben said they were "good" and helped him realise his family were proud of him.

In our penultimate session I invited Ben to prepare some advice for other children who faced similar difficulties with Worry on how to overcome it and keep winning. This taking-it-back practice was intended to empower Ben and embed his new narrative by sharing it with others.

Outcome

Post-therapy Ben's SDQ scores had reduced to the 'normal' range. During each session Ben rated the degree to which Ben versus Worry had control over his life. Ben's rating of the control Worry had over his life decreased each week (and hence his own sense of control increased).

By our final session Ben announced that Worry no longer bothered him when he touched seashells, went in the sea, touched rubbers, used paints or pens, touched wooden furniture, ate garlic bread, played outside near mud or grass, had to do his buttons up or put his pyjamas on. In fact, the only thing Worry still convinced Ben to ask for reassurance about was whether he had cleaned himself completely after using the toilet. However, Ben was only asking for reassurance about this once or twice a week and told me Worry had not bothered him when he did not ask for reassurance.

Ben said that therapy had helped him "not to worry" but he was not sure why and Mr and Mrs Brown felt that Ben had regained his confidence over the three months and become a "happy, fun child" again.
OLDER PEOPLE

CASE REPORT SUMMARY

A Narrative Approach to Working with an 82-year-old Woman with Charles Bonnet Syndrome

APRIL 2007

YEAR 3

In order to preserve anonymity for both services and individuals, identifying information and details have been altered through the report and all names used are fictitious. The client has given written consent to this report and the original consent forms are kept in the client's hospital file.
**Reason for Referral**

Peggy Morris, an eighty-two year-old woman, was referred to the psychology department within the Community Mental Health Team for Older People (CMHT) by her Community Psychiatric Nurse (CPN). The referral indicated that Peggy had Charles Bonnet Syndrome, and that her CPN felt there was a behavioural element to her symptoms.

**Presenting Problem**

Peggy reported that she suffered from macular degeneration (MD) and Charles Bonnet Syndrome (CBS) and as a result saw vivid hallucinations, such as bugs, people, animals and dye coming out of her body. Although Peggy was aware that these hallucinations were a result of her impaired vision, she found them incredibly distressing and spent approximately four hours each evening washing herself to remove the dye. Peggy's hallucinations started six years previously, at the same time her eyesight began to deteriorate. At this time, she had been housebound for several years and her husband had developed Alzheimer's Disease. At the same time Peggy had a bad fall and was hospitalised. Peggy recalled that it was during her time in hospital when her hallucinations became particularly distressing. However the nurses on the ward colluded with Peggy, for example by saying that the reason she could see animals outside the hospital window was because there was a zoo there.

**Assessment**

I met with Peggy over three weekly sessions in her own home for the initial assessment.

**Formulation**

A biopsychosocial framework encompassing narrative ideas was used to guide the formulation.

CBS is a condition that usually occurs in older people and is characterised by visual hallucinations in conjunction with deteriorating vision, but without the presence of psychological disorder. Peggy suffered from MD and despite recognising
that her hallucinations were not real, still experienced them as very distressing. Peggy noted that they became more distressing when she was lonely or stressed.

Peggy had a hearing impairment, which meant that alongside her visual impairment she was unable to participate in a number of activities provided in her warden-assisted block of flats. The social model of disability would suggest that Peggy was disabled by her environment and others rather than her impairment. A broken lift, not Peggy's mobility difficulties, stopped her from participating in social activities. Furthermore the pervasive ageism within our society is also likely to have functioned to oppress Peggy. It could therefore be the case that factors in our society that disempower people with health impairments and older people took away Peggy's voice. Furthermore, the prevalent discourses about older people might have made it easier for more powerful others to author dominant stories about Peggy (such as being an 'attention-seeker').

For Peggy, 'weak', 'naïve' and 'attention-seeking' could all be considered 'thin descriptions' and in turn, such 'thin descriptions' could be seen to have led to a 'thin conclusion' about Peggy being 'needy' or an 'attention-seeker'. This dominant problem-saturated story meant that other instances that fitted with the plot of Peggy being an "attention-seeker" were more easily remembered and privileged (such as telephoning her daughter when she was distressed) and therefore the dominant story gained thickness and richness. Peggy had no control over authorship of this story. Letters were not copied to her and the CPN discussed Peggy's progress with her daughter separately from Peggy.

**Intervention**

During assessment Peggy referred to a desire to write a book for other people experiencing similar symptoms to her own, in order to destigmatise CBS. After a discussion we decided that this book would form the focus of our work together. I met with Peggy for ten, hour-long sessions over a period of three months. We concluded our sessions with a celebration of Peggy's achievements, by sharing a cup of tea together and exchanging cards and letters.
Peggy's decision to write a book for other people could be conceptualised as the ultimate 'taking-it back practice', as she decided to share her new narratives, literary records, knowledges or skills with other people facing similar difficulties.

Peggy and I decided we would audio-record our discussions and I would transcribe these to form the basis of the book. During our discussions I used relative influence questioning to map the influences of the problem on Peggy's life, and Peggy on the life of the problem. As the subject of Peggy's book was her experience of CBS, my initial questioning focussed on the effects of CBS on her life and relationships.

Whilst writing the book, Peggy began to describe unique outcomes or events that would not be predicted by the dominant problem-saturated story. I was curious about these events and used 'landscape of action' questions to begin to develop a story linking these events with other events in a sequence, across time in accordance with a plot. I also asked 'landscape of consciousness/identity' questions which enquire about what meaning is given to an event.

Peggy and I decided that I would recruit members of the psychology department as an outsider-witness group, to be an audience to Peggy's book within a team meeting. After reading the book I asked members of the department to write a letter to Peggy describing how the book resonated with them. I compiled these letters and read them to Peggy in our final session.

Outcome

At the end of our sessions Peggy had reduced the time she spent washing each day from fours hours to just half an hour. She felt pleased with this as she felt it meant the Bugs were not interfering in her life. Peggy also commented that her daughter and grandson had remarked that she had reduced the amount she spoke to them about the Bugs. Although this was not a goal of therapy, it is noteworthy that Peggy reported she enjoyed her time with her daughter more as they looked through old photographs together and reminisced together. Peggy reported that by the end of our sessions she felt she had "come to terms" with CBS and that her influence over the Bugs was greater than their influence over her.
RESEARCH DOSSIER

This section comprises of the research undertaken over the three-year course. It contains the Research Logbook; Service Related Research Project; abstract from a group Qualitative Research Project; and the Major Research Project.
RESEARCH LOG CHECKLIST
### RESEARCH LOG CHECKLIST

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SERVICE RELATED RESEARCH

PROJECT

"It's all the little things that make a service what it is":

The Essence of Care for a Service for People with Eating Disorders

JULY 2005

YEAR 1
1. ABSTRACT

OBJECTIVE: While Essence of Care (Department of Health, 2001; 2003a) has been developed as a generic, comprehensive benchmarking toolkit to evaluate quality care within the health service, its appropriateness for furthering the clinical governance agenda in specialist mental health services is under-researched. The present exploratory study aimed to investigate whether the areas of care identified by users of an eating disorders service were compatible with those described in Essence of Care.

DESIGN: A cross-sectional focus group design was employed in which qualitative methodology was used to elicit what service users perceived to be the key components of care that constituted a quality service.

METHOD: Seven participants from a specialist eating disorders service, ranging in age from 20 to 39, participated in two separate focus groups regarding their ideas about quality service provision.

RESULTS: A thematic content analysis was conducted on the data from the focus groups. Four overall themes with several sub-categories emerged. The themes included: package of care, atmosphere for recovery, resources, and wider systems.

CONCLUSIONS: Although initially the areas of care identified by Essence of Care (DoH, 2003a) did not appear to correspond with those generated by the current study, several key themes ran through both sets of standards. These included issues of individuality, staffing and the importance of communication between services, professionals and service users.
2. INTRODUCTION

In recent years capturing the essential components of care that constitute a quality health service has become an important part of the Clinical Governance agenda (Chambers & Jolly, 2002). Essence of Care (Department of Health (DoH), 2001; 2003a) is a benchmarking toolkit that aims to enable practitioners to compare, share and develop services to provide high quality care for patients. The benchmarks included in the toolkit cover nine areas of care, including: communication, continence and bladder and bowel care, personal and oral hygiene, food and nutrition, pressure ulcers, privacy and dignity, record keeping, safety of clients with mental health needs and principles of self-care. However, despite contribution from patients, carers and professionals, Essence of Care (DoH, 2003a), which was devised to measure quality care and best practice within all health services seems unsuited to consider the needs of people using specialist mental health services. Although the Department of Health (2003a, pp.2) state that the nine areas identified as the most significant in impacting upon patient experience as “re Relevant to all health and social care settings”, little information exists about its’ relevance to specialist mental health services.

Although quantitative measures are traditionally employed to evaluate service delivery, according to Clifford (1997), the value of a service is determined by whether or not it meets the needs of the users of the programme. Therefore, it is of fundamental importance to establish what the users’ needs are, and if they perceive these needs to have been met.

A core theme highlighted throughout Essence of Care (DoH, 2003a) is that of tailoring care to individual needs. However, this appears incongruous with the use of a generic toolkit, which proposes that the same elements will constitute quality care for everybody. Few studies have investigated how service users with an eating disorder construe quality care and service provision (Colton & Pistrang, 2004). However, where this has been investigated, specific therapeutic strategies and a supportive and understanding environment were found to be key components of care that service users found helpful (LeGrange & Gelman, 1998). This appears to have little bearing on those nine areas identified as most significant in impacting upon patient experience by Essence of Care (DoH, 2003a).
The aims of the present exploratory study were therefore threefold:

1. To use qualitative methodology to examine what the users of a service for people with eating disorders considered to comprise quality care and service provision.

2. To consider whether the areas of care highlighted by the Department of Health (2001; 2003a) as those being most important in the delivery of quality services corresponded to those identified by the users of an eating disorders service.

3. To explore to what extent service users perceived that their local eating disorders service was meeting the benchmarks they had set.

3. METHOD

3.1 PARTICIPANTS

Participants were seven females aged between 20 and 39 years of ages (M = 23 years 9 months, SD = 7.064) who were currently engaged in an Eating Disorders Service at a hospital in the South-East of England. Three participants had a diagnosis of anorexia nervosa, two of atypical anorexia nervosa and two of bulimia nervosa. Invitations and information sheets (see appendix i) were sent to all service users in the day programme and an outpatient therapy group, and to individuals attending outpatient appointments who had previously expressed an interest in participating in discussion about the development of the service.

3.2 MATERIALS

A list of prepared questions developed using the principles suggested by Krueger and Casey (2000) was used to structure the focus groups (see appendix ii), which were audio-recorded using video-recording equipment.

3.3 DESIGN
A cross-sectional, single-category focus group design (Krueger & Casey, 2000) was employed in which qualitative methodology was utilised to elicit in-depth information regarding the opinions of service users.

3.4 PROCEDURE

Two focus groups were conducted and facilitated by a Trainee Clinical Psychologist who was unknown to the participants and assisted by a Clinical Psychologist working within the service, who was known to all participants. The groups lasted between 50 and 80 minutes and were audio-recorded and subsequently transcribed verbatim (see appendix iii and iv). The questioning route consisted of open-ended questions to facilitate discussion about individual's experiences of services and opinions about what constitutes a quality service. Participants were informed of their right to withdraw at any time without any implications to their clinical care and were advised that their results would be kept completely confidential and anonymous.

3.5 DATA ANALYSIS

A thematic content analysis (Miles & Huberman, 1994) was carried out on the data from the focus groups. The transcriptions were initially reduced to general statements that could be identified as common themes in the data. Both of the focus group facilitators then independently organised these statements by identifying units of meaning to illustrate each piece of information relating to a specific theme. A comparison of the themes generated indicated good inter-rater reliability. The thematic analysis resulted in four themes, each with sub-categories regarding what constitutes quality care within an eating disorders service. The themes are presented below, with quotations from the transcripts to illustrate the meaning of the categories.
4. RESULTS

4.1 PACKAGE OF CARE

"a programme that incorporated a wide range of therapies to suit individual needs"
(participant A: 126)

4.1.1 Therapy

The content of an individual’s package of care was important to their experience of the service. It was recognised that “different people gain out of different kinds of therapy” (participant D: 140) and a variety of input including dietetics, cognitive-behavioural, and educational approaches were discussed. Education on a range of subjects was a particularly valued component of therapy. The importance of therapy in both group and individual formats was recognised and the optimal size of groups discussed.

4.1.2 Structure and Consistency

Participants described the structure contact with a specialist service gave them as a stabilising influence in their lives. Knowing “what to expect” (participant G: 39) was thought to be important for both patients and staff and contrasted with the chaos and inconsistency that characterised trying to access a suitable service in the first place.

4.1.3 Reassurance

Participants described reassurance as a particularly important feature of treatment that made them feel understood, and not judged for their behaviour. Reassurance about food and that they weren’t “completely crazy” (participant G: 17) and could be helped all contributed to a supportive atmosphere that the participants valued.
4.1.4 Normality

A number of participants described losing sight of 'normality', particularly after inpatient care. A key role of services was seen as helping people to reintegrate and "getting back into...doing normal things" (participant C: 141).

4.1.5 Long-term Support

It was highlighted that services need to be aware of the idea that recovery takes time and support this process through the provision of long-term support.

4.2 ATMOSPHERE FOR RECOVERY

"We're not all patients, we're like people to you" (participant B: 289)

4.2.1 Individuality

The concept of 'individuality' was significant in influencing participants' experience of care within services. They felt that high quality of care was apparent when they experienced "a programme that incorporated a wide range of therapies to suit individual needs, bearing in mind that people are different and everyone doesn't change, gain weight or progress at the same rate" (participant A: 126), whereas felt that poor quality of care was experienced when they represented just another anorexic or a statistic. Moreover, standard packages of care, despite being comprehensive and providing equality were felt to ignore individual needs.

4.2.2 Holistic Approaches to Eating Disorders

One group in particular stressed the need to view an eating disorder holistically, rather than just as an issue of weight: "you need to deal with the other issues don't you, not just the weight" (participant D: 250). In their opinion good services were those in which all aspects of the eating disorder were dealt with and weight gain in itself was not equated to recovery. Treatment solely focussing on weight gain was not deemed sufficient, but on the other hand was recognised as necessary for managing risk.
4.2.3 Philosophy of Care

Participants described the balance of responsibility important in a service. Some participants felt that quality services gave them “someone to answer to” but at the same time provided them with “responsibility for our own treatment” (participant A: 33;101). A similar dilemma was that between safety and challenge and to what degree patients needed to be pushed to make progress rather than left to set their own pace of treatment. Key components to striking the correct balance seemed to be encouragement, guidance, positivity and recognition of achievements.

4.3 RESOURCES

“The people were more important than the building” (participant E: 64)

4.3.1 Staff

Relationships with a variety of staff were seen as a key aspect to a quality service. Issues of stability and continuity in staffing were highlighted by participants who described the difficulties in developing trusting relationships with staff fulfilling short-term contracts. Moreover specialist training and the importance of shared communication (e.g. in terms of language) were discussed.

4.3.2 Physical Environment

The physical environment was briefly commented upon, although it was agreed that “the people were more important than the building” (participant E: 64). The pros and cons of a hospital versus community setting were discussed.

4.3.3 Support from Other Clients

Participants who were part of a therapy group described how the support they gained from other members reduced isolation and provided alternative points of view. It was also deemed beneficial to see other members of the groups progressing, as it suggested the potential for progress in oneself.
4.4 WIDER SYSTEMS

"well I think it would just help if they were.....to raise awareness" (participant G: 48)

4.4.1 Pathway to Care

The referral and assessment process was seen as crucial in impacting upon people's experience of treatment. A significant proportion of individuals had negative experiences of the referral and assessment procedures when accessing an eating disorders service. People described feeling judged, misunderstood and not taken seriously. Services that people had to attend in order to gain access to a more specialist service were seen as unsatisfactory in providing useful information during the waiting period and participants found having to repeat their stories to various different people very painful. People also described how often referrers were unsure about the best place for individuals or were unaware of the eating disorders service. Conversely, clinicians who actively supported clients in the run up to them becoming engaged in a more appropriate service were highly valued. It was suggested that "at the assessment you need some reassurance that you're not past it, you can be helped and that whatever happens in the assessment they do, whoever's doing it...is going to point you in the right direction, so if this isn't the right service for you we're going to point you in the direction of someone who can tell you what is" (participant G: 177).

4.4.2 Education to Different Systems

A key factor related to assessment was the role of specialist services in educating referrers (including mental health services and GPs) about the facilities they offer. The maintenance of open communication between services was also thought to indicate a quality care package.

Participants were clear that services needed to provide support, information and education for carers and relatives and to ensure that people were aware that this support was available. However, the issue of confidentiality arose, as sometimes this could act as a barrier to sharing of information. The role of eating disorders services in educating schools in early intervention was discussed.
5. DISCUSSION

5.1 QUALITY CARE IN A SERVICE FOR PEOPLE WITH EATING DISORDERS

The findings of the current exploratory study elucidated several key areas that participants felt were crucial in determining the quality of care they received from an eating disorders service. A significant indicator of quality care mentioned by participants in both focus groups was the actual package of care or programme designed for an individual. This is consistent with previous findings, which suggest that factors such as psychoeducation, a supportive and understanding environment and specific therapeutic techniques are particularly valued by people experiencing therapy for their eating disorder (LeGrange & Gelman, 1998).

Participants in the current study described a number of dilemmas treatment posed including: the balance between physical and emotional aspects of their eating disorder, challenge versus safety, responsibility versus 'having someone to answer to' and being treated as a person rather than 'an anorexic'. Similar conflicts have been found in adolescent inpatient eating disorder units (Colton & Pistrang, 2004) and the current study indicated that the way in which a service managed these conflicts was a significant determiner of individuals' experience of care within that service.

Other contributions to an individual's experience of quality care included taking a wider-system perspective in which services played a key role in educating family members, schools, referrers and society about eating disorders and the services they offered. In particular, the need to provide people with a coordinated, structured and supportive pathway into services was emphasised by participants who had been distressed by their experiences of trying to access help.

5.2 ESSENCE OF CARE

Although the nine areas of care identified by Essence of Care (DoH, 2003a) as the most significant in impacting upon patient experience, do not initially appear to
correspond with those generated by the current study, several key themes run through both sets of standards (see appendix v for summary).

Particular components of the Privacy and Dignity benchmarks in Essence of Care (DoH, 2003b) are highly compatible with the philosophies underlying the atmosphere for recovery theme, staffing and the importance of education to different systems. The benchmark of self-care encompasses the conflict service users faced between responsibility and handing over control to someone else, and the availability of information for service users and their carers about services offered. While the communication benchmark is significant in areas of staff, the wider system and individuality, the benchmark relating to record-keeping and its emphasis on partnership between the “patient and professional” (DoH, 2003c, pp.4) is fundamental to the philosophy of and pathway to care themes.

It is notable that the benchmarks covering continence, personal and oral hygiene, food and nutrition and pressure ulcers were not comparable with themes generated in the present study. Furthermore, the theme ‘package of care’ did not relate to the areas acknowledged in Essence of Care (DoH, 2003a). It is possible that these two areas represent specific features of care that are idiosyncratic to the service that is delivering them. Therefore, in a general medical setting dealing with pressure ulcers may be an important component of quality treatment. However, in a service for people with eating disorders reassurance and education represent a key aspect of treatment.

5.3 BENCHMARKS IN A LOCAL EATING DISORDERS SERVICE

Participants described aspects of their local service in largely positive terms, although a number of recommendations for service improvements were identified (appendix vi). Service users valued being treated as individuals by staff and noted that the ethos of the service achieved the correct balance between the conflicts posed by treatment. Furthermore, people experienced the holistic approach to eating disorders adopted by the service constructive. With regard to improvements, people observed that practical alterations such as flexible service opening hours, heterogeneous groups and providing additional support immediately after entering
the day programme would be beneficial. However, particularly striking was the consensus that improvements were necessary in accessing the service from the outset. Some individuals recounted painful experiences of feeling judged, ashamed and dismissed when attempting to access help and it is here that the role of a specialist service in providing training and education to other services is emphasised.

5.4 LIMITATIONS

The present study had a number of limitations that are necessary to bear in mind when interpreting the results. Firstly, the sample of service users in the current study was small and self-selected. This may indicate that these participants were particularly motivated and possibly biased to report positively about the service. Furthermore, although experiences of other services were drawn on, the sample all came from the same service, which may have implications for generalising the findings.

One of the facilitators of the focus groups was a member of staff who was known by all participants. It is possible that this may have impacted upon the validity of the data as participants may have felt reticent about speaking freely, although the evidence of suggestions and criticisms throughout the groups indicates that the participants felt somewhat able to speak freely.

Finally the qualitative approach employed by the study did not allow systematic evaluation of Essence of Care (DoH, 2003a) as an instrument. However, this was not the aim of such an exploratory study, which instead set out to prioritise the needs of a service's own users when thinking about evaluating and improving the service, using Essence of Care as a framework for exploration.

5.5 FURTHER RESEARCH

When Essence of Care was devised, input was gathered from service users, carers and professionals in order to decide upon the central elements of care that constitute a quality health service. It would therefore be interesting to repeat the focus groups with professionals and carers.
The findings from the current study suggest that the Privacy and Dignity benchmark (DoH, 2003b) is particularly appropriate to the concerns of individuals using an eating disorders service. In order to progress the clinical governance process in the service described in the current study, Essence of Care could be used to evaluate best practice with this benchmark.

As described, the sample size was small, and it would be impractical to run focus groups or interview every individual who attends the service. It is therefore possible that a questionnaire could be designed to encompass the different themes illustrated by the current study to assess service user satisfaction.

However, the ability of such an instrument or indeed of further focus groups to truly capture what quality care within a service genuinely represents is unclear, as one participant clearly articulated: "everything's important about a service, so just to pick one thing out and say that's the most important I don't think you really can. It's all the little things that make a service what it is" (participant B: 448).
REFERENCES


University of Surrey
PsychD Clinical Psychology
Service Related Research Project
Ethical Scrutiny Form

The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust's ethical committee.

Name of Field/Placement Supervisor:
Signature of Field/Placement Supervisor: 

Name of Trainee: Suzanne Gray

Title of SRRP: The Essence of Care of a Service for people with Eating Disorders.

Date: July 2005
APPENDIX II: INFORMATION SHEET FOR PARTICIPANTS

A Personal Invitation.

What is the purpose of the research?
You are being invited to take part in a focus group being carried out by the staff at the Eating Disorders Service. We are investigating how people feel about the service and what improvements they think could be made.

Who is carrying out the study?
A Trainee Clinical Psychologist is carrying out the study and will be facilitating the groups with a Clinical Psychologist who works within the service.

What does taking part involve?
Taking part in the study will involve participating in a focus group, which will last between one and a half and two hours. There will be about 5 other people in the group who have used services provided by Eating Disorders Service, what works and what doesn't. You don't need to prepare anything for the group and you won't be asked to share any personal information about yourself or your treatment. We simply want to get some ideas from the people who are most important in our service - the people who actually use it.

If you don't want to take part you do not have to give a reason and you will not be asked about it again. Similarly, if you do agree to participate you are free to withdraw at any time during the project if you change your mind - simply contact (contact details below).

Will what I say be confidential?
If you decide to take part in the study, anything you say in the group will be completely confidential and anonymous. We will audio-record and later transcribe the group discussion.

If you have any queries at all about this study, please contact [name] Trainee Clinical Psychologist:
Address:
Phone:
Email:

removing any identifying information.
The results of the study will not be presented in any form that can reveal your identity.

Why is my reply important?
This is your chance to let us know about your experience of the Eating Disorder Service. The more people who take part, the more representative the findings will be.

After the study is completed a report will be sent to you to let you know what we found and how it has helped us in developing the service.
APPENDIX III: QUESTIONING ROUTE

Opening Questions *(getting everyone to talk early in the group, answerable in 30 seconds)*
- Tell us who you are and how you're feeling about being here today

Introductory Questions *(introduce topic of discussion — ask participants how they see service, when they first experienced service)*
- What is the first thing that comes to mind when you think of the service?
- Thinking back to before you came here, what did you hope it would be like?
- What was your first impression of the service when you started coming here?

Transition Questions *(move the conversation onto key questions)*
- What do you think is the role of the service?
- If you were asked to design a service for people with eating disorders, what would you start by doing?

Key Questions *(2-5 key questions needing 10 minutes discussion each)*
- What do you think are the most important things in a service for people with eating disorders?
- What do you think the staff think are the most important things in a service for people with eating disorders?
- What is good about this service?
- What could be improved or changed and what would you do to make these improvements?
- Considering what you have said are the most important things in an eating disorders service, do you think the service is doing these things?

Ending Questions *(all things considered question, summary question, final question)*
- Suppose you had one minute to talk to the Chief Executive of our NHS Trust about the service. What would you say?
- Of all the things we've discussed, what is the most important to you?
- Summary. How well does that capture what was said here?
- Is there anything that we should have talked about, but didn't?
APPENDIX IV: TRANSCRIPTION OF FOCUS GROUP 1

1. S: Instead just going round and asking everyone to say their names and what they're hoping to get from today really. Shall we start with K?

2. Laughter

3. K: Oh Thank you! Well I'm looking forward to this because it's the first one we've done and I'm hoping it's not going to be the last one. I think we've been talking about doing one of these for quite a while now haven't we? In fact, this group, some of the people in this group discussed it quite a while ago. Ummm I'm looking forward to hearing people's opinions, and it's nice to get people together. Also people who wouldn't normally come in. So thank you particularly to **** who won't have met anybody. We will put the name cards up for you - yeah?

4. S: ****?

5. A: I'm ****, and I wasn't expecting to get anything out of today. I just thought it'd be nice to do something useful to help society and mankind

6. Laughter

7. S: That was very deep

8. K: Well that totally eclipses me!

9. E: How do we follow that?

10. Mutterings

11. B: Hi I'm B. What was I hoping to get out of today? Don't know, just to hear other people's opinions of the service. Hopefully to help changes where I feel that maybe could be improved. Really

12. K: Brilliant

13. C: I'm C. I just come once a fortnight to see K as an outpatient. I just wanted to give my contribution on the outpatient service as well as I've had experience of inpatient as well.

14. D: I'm D and I'll just go along with B, no A.

15. E: No A was the deep one

16. A: I'm A.

17. D: I didn't expect to get anything, just to help the service really

18. E: I'm E. yeah I just thought it would be quite interesting to find out what other people have found helpful and what other people didn't

19. S: And I'm S and I suppose I'm just, I have no idea about any of the groups or the outpatient services and what clients actually think of them. So I'm really looking forward to hearing about those things.

20. S: Ok shall we get cracking then?

21. K: Shall we put the name cards up, cos I'm thinking particularly for C. You'll have a terrible job remembering

22. A: Here?
23. K: That's it. Yeah

24. A: Cos we don't need to see our own, cos we know who we are

25. Laughter


27. S: Ok so first question is asking you to think back to before you started coming to the [name of service]. Um I was wondering what you think your hopes were before you started coming?

28. E: Miracle cure I think, was my hope. Turn up the next week and got over it. I wouldn't need to come any more. Long-term - more realistic I expect.

29. Silence

30. S: Anybody else have similar or different hopes?

31. A: I think it's the only place, cos I, I'm not very good at talking to people about anything, especially important stuff. It's the only place that I can talk about eating difficulties and things with people with the same sorts of issues [quiet feel much the same] so it would be a much lonelier world without it

32. E: Ummm. Definitely. I mean meeting other people. You feel isolated when you first start off and you've got other people, normal people (laughs) who've got the same kind of problems. Quite interesting, very interesting and supportive. Very supportive.

33. A: Mmm. And it's motivating to keep trying to change what needs changing. You've got someone to answer to, well vaguely.

34. E: Ummm.

35. C: I first came here about, probably nearly four years ago now. Just seeing K, and um I did have a brief go at the inpatient for about a week, but at the time I was very ambivalent about umm everything really and it didn't really work for me. But since then I have moved on and been able to use, particularly the outpatient work [quiet] [pause] That's helped me.

36. B: Support network as well, isn't it? You know that you've got, you've got people there if you need them you know you know that you've got somewhere to go if there's been something that's you know been worrying you all week, you know that there's somewhere to go where people are going to listen you can look at things you know and they'll understand or help you. Give their point of view or make suggestions

37. S: And do you think that before you started coming that's something you hoped would be here or do you think you had different hopes to that?

38. B: To be honest with you I can't really remember what what I thought at the beginning I knew it was just, obviously it was important I knew I needed that help. I suppose you know everyone hopes for [pause] not to have to live with it forever. Hope maybe one day that it might disappear into the background.

39. E: No, it will [laughs]

40. [laughter]

41. D: I think I hated to come here I hated the thought of coming for help. So I suppose I gradually came round to the idea I hoped that I'd be cured. I think that's me....
42. S: I think that's something that can be quite difficult to admit to sometimes, particularly within a group like this, that actually you really didn't want to come here in the first place, but actually but I don't know if other people

43. D: I wasn't entering into a group then, it was just sort of one-to-one therapy and the dietician. That was when I was sort of like first diagnosed really.

44. E: It's difficult though, difficult coming into a running thing everybody knows why I'm here [laughs]. You say nothing for quite you know and then you realise that everybody's quite supportive and it's not so bad the next time sort of thing

45. B: I think I was very dubious the first time I went into a group because you do have different characters within a group and sometimes you do feel like you just want to sit back and it does take a while to build up confidence. I think you have to trust the people that you're in a group with you know if you don't have the trust but they're great then you're never going to open up and you know you aren't going to get out of the group.

46. S: Can any of you remember what your first impression was when you walked through the doors?

47. A: It was years ago

48. E: It was at the other...

49. B: building yeah

50. E: I hope this building doesn't fall down [laughs]

51. B: Yeah, no, it is much nicer here

52. E: There were lots of scaffolding bits holding things up

53. B: Oh God yeah

54. E: Do you remember?

55. C: It was quite chilly.

56. B: It was freezing in the winter wasn't it? We used to have the heater on didn't we and sat by the heater!

57. E: I remember I had a one-to-one thing right up in the very top up four flights of stairs and I was seeing ****

58. A: all those stairs

59. B: Oh God yeah

60. E: And in the middle of summer the heaters were still on. I was boiling and the windows would be open and I'd sit there absolutely roasting. Even though in the winter it was freezing cold.

61. S: So first impressions from somebody starting here would probably be quite different from somebody starting at the old building?

62. K: I hope so!

63. B: Oh my goodness yeah. A lot more modern here.
64. E: I think it was more than that. The people were more important than the building.

65. B: Yeah:

66. E: Especially going into the groups and things.

67. B: The old people have come here with us, so...

68. E: I was in a completely different group and we...

69. A: I was in a different group... and we all joined up

70. E: Did you and I join at the same time then?

71. A: No I was there before

72. E: You were here before me

73. A: I was coming for, it took me several years to get to the group. I was in outpatient treatment then about four years later I got a letter saying 'you've been invited to the transition group'. That was four years after I'd started individual therapy.

74. D: I think the bonus of the other building was that it wasn't in a hospital as such

75. B: Yeah!

76. E: Mmmm

77. D: So now you think sickness - hospital

78. Others: agree

79. D: Whereas the other place was just like a house really

80. B: It was yeah

81. E: It was like going into a movie. Yeah I thought that as well - coming to a hospital is different to going to that old building, which was always ....

82. D: I suppose just with it being a house you can sort of deceive yourself why you're going there in some respects. Cos now you know you've got a hospital attached to it

83. S: Ok so shifting the focus a little bit, what do you think the role of the [name of service] is?

84. B: Support, guidance and you know there as you know, obviously for information Just so you learn things about, learn what an eating disorder is all about

85. D: the Dietician's input as well

86. B: Help with structure

87. A: One-to-one therapy... and no mini-bar

88. [laughter]

89. K: No mini-bar. We did have ______

90. E: We did have tea in the old days
91. B: Yeah I know, cutbacks affecting everywhere!

92. ?: We're being really stupid.

93. E: We're just being rude.

94. A: What was the question?

95. [laughter]

96. S: The role of the service?

97. E: Supportive

98. K: We've kinda got support, guidance, information, structure, therapy, dietetics

99. E: It gets you back on track. It's quite easy to fall off. You kind of...you know what I mean You come here and I think in a group you know...if we weren't here I think we'd be slitting our wrists [laughter] and next week I want to do them properly

100. B: I suppose it looks at like the whole of the eating disorder, so you know not just mental, but physical and I mean everything that goes with it as well.

101. A: It does give you responsibility as well for your own treatment. Whereas when I was an inpatient there were targets, weight targets that you had to be done in a certain amount of time and if you didn't do it you got discharged or thrown out or whatever. And so it was all therapy done to avoid, not therapy, weight gain was just done to avoid losing your therapy and getting kicked out. Whereas you can negotiate targets here and basically work at ....

102. B: ...your own pace

103. C: You have a say in your treatment and your care and what works for you and you do know what works for you. You need them for support and guidance.....

104. B: It really helps when you work with a group and you get to know them and you see other people progressing. Even if other people make a slow progression or even over years maybe. It really helps you seeing progression in other people as well.

105. S: And what makes you think that helps?

106. B: Sorry what was that one, start again? I don't know I sometimes you think 'maybe things do get better' and if you see things improving for other people then you think 'oh maybe it's more likely for things to improve for yourself'.

107. K: It's interesting actually hearing people compare experiences with other services. Has everybody had experiences of another.....***** have you?

108. I think probably everyone else has. So in a way you're comparing it against itself aren't you, whereas perhaps compared to inpatient or other services. It's quite interesting hearing how, how it does compare, how it's different. Are there any other ways you'd say it's different from other experiences, from inpatient or...?

109. A: Inpatient is done so quickly and so big weight gains in one go, there's not much hope unless you're superwoman and most people can't actually deal with doing that much in that short space of time. And so it's not like it's long-lasting that much anyway
D: I think the sort of the ethos of [service name] to me is different, but it em, it's not so weight-focused. You know recovery here isn't so much, you have to be this weight, whereas you know other experiences I've had that was what weight meant - recovery. Whereas here it's more about looking at the other things that contribute to it as well.

S: Have other people found that as well?

C: Yeah. Sometimes in inpatient there was that [inaudible] and that's not provided by [name of service], but they're there while you're going through that and carry on when you come back out and I've come back out had nothing to do with who I had inpatient care with. And in a way that helps as you can detach yourself from that and [name of service] are the people who have helped to build up my life outside of that. in a way I don't think I'd like it if my in-therapy sort of here wasn't working and they could whack me in hospital here. I'd have the same feelings about it and then not want to come back here for sort of individual therapy.

A: You get treated more as an individual here as compared to in hospital. Things like family therapy everyone was made to do and it was really unhelpful. Mother reckons it finished their marriage off for them and it was where I asked father if he loved me and he told me he didn't...but they still carry on with that even though it was obviously not helpful at all really in making things work, but because everyone did family therapy and that's what happened until you left then they carried on. It's good if it's going to help.

E: That must have been really tough?

A: Well yeah father wasn't even living with us, well he was but he only came to the hospital if he had to, but it didn't do anything of any use as far as I can see. But they wouldn't let us stop it because that was what...everyone's still treated the same. You just become another patient and be given a label of anorexic and ... But one's individuality is very important you know!

E: laughs

C: I think everyone gets treated as individuals here. I think, I expect if you looked at everybody's treatment it would be very different. You know, we may all have that same label, but very differences [inaudible]

S: That moves us on quite nicely to the next question, which is if you as a group were asked to design an eating disorders service where do you think you'd start?

S: we're expecting you to have a ten-point plan already, drawn up and ready to give to me!

A: I can't see the value of an eating disorders service without therapy backing it. People to see it as ...actually I used to in some ways as well, when I went into hospital well I thought if I gained weight that'd be it I'd be cured, I could go home world'd be rosy. But it doesn't work like that. That's when everything starts, when you gain weight cos that's when all the feelings start and everything. But um I don't see the value of putting people in hospital, feeding them up and then chucking them out.

E: Ummm
125. A: It needs to be a programme that incorporated a wide range to therapies to suit individual needs, bearing in mind that people are different and everyone doesn't change, gain weight or progress at the same rate and people need a care programme according to one's needs at the time.

127. S: After asking for an easier question that was a very impressive answer!

128. K: You didn't prepare that earlier did you?!

129. E: We had coaching last week!

130. B: Yeah, we found out!

131. K: Don't, don't transcribe that bit.

132. S: No that's off the transcription!

133. K: So to summarise that bit then it's about gaining weight often when things start, everybody's an individual and it's tailoring things to suit...

134. A: Umm it's knowing that weight gain is a symptom of it all, but it isn't the be all and end all of life. And there's other things that are equally important. Look at it more....

135. B: The longer-term picture as well. You know not just like you go into hospital and you come out again and make sure there's something for people then at the end of it. You're not thrown out into the world as such and expected to carry on.

136. D: I think also a lot of people need education in groups and that. It depends who you're marketing it at. Like long-term sufferers, it probably wouldn't be necessary, but if you're recently diagnosed I think you like the education or like self-esteem, assertiveness groups I think cover a lot of the components that go into it, rather than just eating

137. B: Like anxiety

138. D: Yeah

139. B: And all kinds of things

140. D: Plus a lot of people gain out of different kinds of therapy. Like art therapy and things like that

141. C: And socialising and things like that - getting back into.... doing normal things and activities and things like that cos it can be difficult to get back into

142. A: Life skills!

143. laughter

144. E: You're summing us all up! [pause] It's very true though isn't it?

145. A: It is.

146. E: Getting back you know ....

147. A: You lose sight of how to do things normally don't you

148. E: ...into a normal routine. Umm normal becomes some kind of idea. What is normal any more?

149. B: You really can't remember what normal is It's like me. I think what was it like before.
150. E: Exactly! You think what was it like before.

151. B: I don't actually remember what is was like before. And I think 'God! I can't remember now'.

152. E: my fear is that I'm going to pass on my problems to my children. That's the worst thing you know, how to, how to avoid [quietly] the cycle

153. K: So would that be part of the ideal service you'd design?

154. E: Umm.

155. K: Say some more about that. What would you do, what would you like?

156. E: I think it would have to follow on from the education type. Helping people, though I'm sure parents have eating disorders as well as women, but I think I think once you've got children you have this fear of your child going through what you've been through. It's the last thing you'd want more than anything I've got to stop now because if they suffer picked up on *** looked in the mirror and she had a new t-shirt on and went "my tummy looks very fat in this mummy" and I went "[intake of breath] don't say that ***" then how to react calmly and go.....[inaudible]

157. B: How do you do it? Do you like not make food an issue, it's just like try? It must be so hard. That's one of the things that worries me when I have children in the future I think how am I going to cope with that? How am I gonna? I'd be so paranoid about making food an issue you know I wouldn't make them eat if they you know you'd go from one extreme to the other you'd end up not forcing anything because you're so scared of...

158. E: Ummm absolutely. I suppose carrying on from what you said, it's about reintegrating and education it's part of the same thing, it's carrying on with

159. B: Life

160. E: Umm.

161. A: Something I'd like to know more about is

162. E: But it's also about what you said, you know about putting weight on. People look at you and they go.....you know, how ridiculous, of course you should put weight on and they don't understand that fear of weight gain.

163. A: I know

164. E: You stand on the scales and you know you could quite happily put on three kilos and be a healthier weight and be you know, and yet that fear of putting on those three kilos when it actually happens and all of those emotions and thoughts that come back to you that you're working at keeping ....

165. A: I think people understand the concept, but they can't understand the strength of the feelings that make people rather die than put on weight.

166. B: Maybe you could have family education groups as well? Maybe something some kind of education group for families, for example if it is your child or you know things like that where they could come along and get information. Cos I know obviously when I lived at home my parents went out and they didn't actually go to.. but they went out and they got lots of information cos they wanted to know and they wanted to try and understand and if they knew that they had somewhere to go it would have been a lot easier for them if they could have asked somebody questions and you you know.
167. E: My dad...I don't think my parents made any effort to go anywhere ever. They just sent me off to be treated, expecting me to come back cured. That was it. It was like no we'll pay for you to do this now, go there. And we'll send you there and that's what you'll do. And because we're spending a lot of money on it, that should make sure you'll try your best and do it. There was a complete lack of understanding that I was of course...also yeah it's about educating society I suppose.

168. D: I think that's quite important, cos sometimes when you're living with people it's hard to tell them how you're feeling about it. So to have somebody to sort of do it on your behalf....

169. A: Though my mother kept wanting to try and find out when I was in hospital, but because the patient has to give consent, they wouldn't tell her anything at all. They didn't actually ask me if I wanted my mum to know, and she kept asking questions, and they wouldn't tell her anything about anything.

170. D: Yeah but it could be general as opposed to A says...

171. [agreement]

172. B: But even if there was I know it sounds funny, but even if there was some form of group but like for like family members

173. D: There are carer's groups.

174. B: Yeah but I don't know if they like run them like, I haven't seen them. But like yeah

175. A: Like Al-anon.

176. E: Ummm.

177. B: Yeah, like..

178. A: They have alcoholics anonymous groups for family members don't they?

179. [agreement]

180. E: They have drug support for family members.

181. B: Yeah that kind of thing. I just, there is one

182. A: There is one

183. E: Is there?

184. D: Don't you run one here - a support group?

185. K: Once a month yeah

186. ?: That's really good.

187. B: I never knew about that.

188. K: I'll get you some information on it.

189. B: Well I don't think my husband would [laughs] Well obviously I don't, haven't lived at home for quite a long time now!
190. S: I suppose an interesting thing that's brought up is the accessibility of information about what is available really.

191. E: Mmm.

192. D: It's not there. I think that's a you know, People say it's not there but I'm mean I've talked to doctors and things like that and they've never heard of you. Whether it's because I come from **** but that's not a million miles away. But I've never..

193. E: No

194. D: A lot of people are like 'where's that, what do you do there?' sort of thing, but I don't know how you'd go about advertising your service

195. B: It just has to be, I was just lucky

196. E: Yeah I think that as well, I don't think ....

197. B: Because my first GP didn't do anything! Did absolutely nothing and it wasn't until she left and I got another GP and he said "why on earth hasn't she referred you before?".

198. E: My first GP said "I've never seen a case like you in my life. I've been a doctor for 40 years and I've never seen anything like this".

199. A: Bet you felt good!?

200. E: Yeah I felt really awful then [laughter]

201. A: I can't see the value of any doctor working in an eating disorders service that isn't trained thoroughly in eating disorders.

202. E: Umm

203. A: It's like sending someone who's got an in-growing toenail to a cancer specialist or someone.

204. [laughter]

205. B: Mmm yeah they have to have had a trained. I expect they do though. I think the doctors who work here must have done training in specialist. They must do.

206. C: inaudible

207. E: I found it strange that my GP took a month or more to really try and find out.....he was very nice, very supportive. He didn't know where to start, he had no idea who to phone or what to, who to send me off to!

208. C: But he did make attempts to!


210. C: Yeah. I saw just a general psychiatrist at ******* and that's just general mental health and she had no idea so that was just a waste of time......

211. B: That's like me. I mean originally, years and years ago they had like a little counsellor at our GPs and that's where I started off, but that wasn't specialised enough, it didn't really it didn't really help.

212. C: I think specialist is a big word to underline.
213. A: One that speaks English is always good as well!

214. B: Yes!

215. A: I had some Indian guy and I've nothing against Indians, but you spent half of your time going 'pardon?' and he couldn't understand anything I was trying to say.

216. E: Really!?

217. A: When I was in hospital there was this Chinese lady who came round and she could hardly understand any English.

218. B: Do you have people that go out to like doctors surgeries and educate the GPs about your services?

219. K: We have had yes. We do a rolling programme for health it's an ongoing well you're right obviously it's an ongoing

220. B: issue. Well obviously the GP thing's always changing, but definitely having that updated all the time, so you know the GPs are aware of it.

221. D: Is there some sort of network that you can get into? To sort of promote yourself or....

222. K: Yeah that's a thought isn't it? Yeah.

223. D: Cos maybe that's why like numbers are small getting people into groups because they don't know about you really?

224. K: What are people's experience of.....GPs are figuring a little bit in the conversation. That's an important? Is it almost a little bit depending on who you see?

225. E: That tends to be your first port of call really I suppose.

226. B: It is in the first place where you go. Once you've built up the courage, you've got to build up to go to your GP, so you've got to make sure they do the right thing with the information that you give them. They've got to know what the best thing is. It's no good them, you know, writing it off or you not going to the right places.

227. C: Or saying 'why don't you just eat?'. [needs deciphering]

228. A: Oh yeah, yeah I never thought of that! What a good idea!

229. [laughter]

230. K: Few people had that one?

231. C: Yep.

232. K: Any other ones?

233. E: That's what my mother used to say to me.

234. A: I know. Do they think we're completely stupid and just haven't considered the idea? Oh that's my problem. That's why I'm thin then, is it?

235. S: It sounds as though kind of education at different levels: at the individual, to families and to perhaps referrers and more generic services would feature quite heavily in the ideal service you'd set up?
236. K: Mm. So recapping on what you'd said, you're ideal service would actually be. Ok I'll try and get everything. It would have specialised staff who people could communicate with. Umm it would...actually have input directly to families but there were a few interesting comments there about it being quite difficult sometimes for relatives to get access on the basis of confidentiality, but that it's worth persevering with that because people need information in their own right. Lots and lots of work to advertise sounds like people have had a lot of trouble getting here in the first place potentially. Networking a little bit more. E's comment about the family issues, when you've got children - actually taking seriously that actually mothers and fathers do have feelings of not being seriously not just 'ah it will be ok', but worry about passing on...

237. E: I remember **** from the group before. She said exactly the same thing a couple of times. Her biggest fear was passing on...you know any food fear or food...to her daughter

238. B: If there was someone who could help you manage, or some way that they could you know suggest things that might help. You know any little thing to avoid it. But someone with experience maybe in that as well. I think training is so important you know. The training of staff especially. Even knowing, how to, you know..

239. E: I'd quite like a mothers' group for people who are parents going you know how to deal with these sort of

240. A: Cos pregnancy must be a complete nightmare, well not a complete nightmare.

241. E: Pregnancy was actually fantastic, because I suddenly had to look after myself. And I was not I wasn't number one any more.

242. A: I'd have thought the growing thing

243. E: Oh yeah, but that didn't matter. It was very very funny. Because you know from being completely obsessed with putting on weight and suddenly I was pregnant and that was the only important thing in my whole life. Because I was always so scared about not being able to have children because of my eating disorder.

244. B: And everything you do is going to affect your child.

245. E: You know 'will I ever be able to have children?', well I was pregnant that was it. I stopped drinking, I ate healthy meals. I put on far too much weight. But not you know, I suppose not for......But at the end of it, once I'd had the baby, breast-feeding you lose a lot of weight, he had a milk allergy so I then had to go off all milk, so I was eating no milk, butter or cheese and then you lose a lot of weight because your diet but you look after yourself because of the child not, once I wasn't feeding him anymore straight back to the old bad habits. It's dreadful really - can't just stay on track!

246. B: But it's one of those things that people have got to understand. That it's not going to go away overnight, it's always there in your mind even if you know you manage to go through a few days and you manage to push it there or you're improving and things are happening, but it's still there, it may not always be at the forefront, but you've got to understand it won't go away overnight.


248. K: And services need to accept that. So maybe that would be quite an important thought in people's minds when designing services that this is not a quick

249. B: Someone may go to a good weight, but that doesn't mean the things aren't there. You could just say you know, ok write you off the service, but that could be the end of you.

250. D: You need to deal with the other issues don’t you, not just the weight
251. B: That would just be the end of you. It's so easy to go straight back again. It's so easy to go straight back again. They've got to look at you know, just because someone's gained the weight doesn't mean you don't need the service anymore.

252. A: Life's far harder when you've gained the weight because we don't do it for a laugh. It's because of reasons that people lose weight not just for fun. So you then have all those to deal with.

253. B: You need the support afterwards, just as much as you do....

254. A: Even more.

255. S: So it's something about ongoing support as well? Not just a once you've met your targets

256. B: Ongoing support's so important to keep you, you know to keep you going. I find this service um, I've found especially the group, extremely valuable because I know without it I'd be in lots of trouble. I've found it's really helped me to improve and just knowing you've got somewhere keeps you going. gets you through each week and you've got somewhere for every week does does get you through definitely.

257. D: I think also with the specialist staff I'd make them have long-term contracts so they can't flit in and out

258. [laughter]

259. A: Yeah yeah I've found that one.

260. D: Cos you just sort of like develop a relationship and then they're off and you go back to square one sort of thing and then you have all the trust issues. If it's not possible, you know you can't make someone sign their life away, but it would be nice....

261. B: Yeah definitely to make sure that people are looking for like a long-time

262. D: And knew what they were getting into sort of thing. Like maybe do probation before they sign up...

263. [laughter]

264. D: And then if they like it they could maybe sign their contract sort of thing

265. A: Cos one place I went to I was seen by a registrar which changed every six months and at that stage in the hospital I was at I was having an appointment every three months, so I had two appointments and then I'd get someone new. So spend one session going over it and the next session was a goodbye and then you'd get someone else, so it was a complete waste of time.

266. S: So continuity is important aspect as well?

267. [agreement]

268. S: Ok so drawing together all of the ideas that you've had, what would you say are the most important things in a service for people with eating disorders?

269. A: To see people as individuals.

270. E: I think with this group, it's obviously different cos um you know it's just like seeing people every week and it's almost security and the support, and the continuity and also knowing that the same people are going to be there and if you see K and she knows that you get cross about such and such [laughs]
271. A: And there's

272. B: People know you so you feel you can come straight out and whatever's been happening to you know you can come you can just go straight in, you haven't got to sit there all quietly......

273. E: Nobody's going to judge you.

274. B: No one's going to judge you. You know whatever you want to say you can say it.

275. D: And knowing that you'll be understood I think has been important for me.

276. E: yeah very understanding and supportive.

277. D: Cos if you said some of these things to people without an eating disorder they'd think you know

278. E: Sounds stupid.

279. D: Ummm

280. A: Challenges one's thinking as well. It's a bit easy for it to go wonky I find. And if you've got no other input - I suppose maybe it's a bit different if you've got loads of people you speak to, but I don't speak to anyone else and when it's just all in your head it just goes wonky.

281. C: Encouragement to take risks and things like that.

282. E: Umm.

283. S: Ok so let's shift things slightly, what do you think the staff think are the most important things in a service for people with eating disorders?

284. A: What here or anywhere?

285. S: I don't know about that, what do you think?

286. K: I think both actually. I think it would be quite interesting

287. S: Yeah.

288. E: I think, I think K's always seen us as individuals and she always treats us you know like 'how's that been going?' and you know I think that's really important because that's always, we are all different and she always gone 'So how is this? You know, we've all been worried about this for you, and that for you?'

289. B: And we're all, we're not just patients, we're like people to you. You know us and you remember us - you know everything. It's not like you go to your GP and you tell them something and if you went in the next day they wouldn't remember they'd even seen you kind of thing.

290. E: And six and a half minutes later you're out.

291. B: Yeah it is definitely. Yeah so.

292. A: I think everyone deals with things different don't they?

293. E: Yeah but even if I phone up and '****'s car's broken down and ra ra ra'. I can't remember the lady's name?
K: [administrator's name]

E: She is so lovely and she is you know, so nice, I feel better just having spoken to her! I'm so sorry!

B: Yeah completely

C: Yeah.

B: I think that is so important, when you first walk in the door here whoever's on reception you've got to have a good vibe from them because if you walk in and the receptionist's like a really horrible person you'd be scared off before you even walked in the door! But [administrator's name]’s been here like forever kind of thing!

E: She's so nice.

B: So it's nice that you know her and she knows you!

E: She's like "Oh hello E!"

B: Yeah, so she can know you by name and that's important as well definitely, cos well extremely.

K: But in terms of services generally, cos I'm sure everybody here has had either in here or in other services, general eating disorder doesn't go well and there are things I'm sure there are things about coming here that wouldn't be perfect, but what would be the things perhaps [pause] I suppose that may not be so positive or perhaps you'd like to see a little bit more of or less of?

B: I'll tell you one thing and I know we probably all find it, I mean it's very hard cos people have their working hours but it's a pity they didn't have more evening groups.

A: Yeah, yeah.

B: Cos our problem is that we all work and it is is extremely difficult. I'm lucky that I've had a very good boss so she has given me, but we're lucky we're allowed the time. but I bet you'd find a lot of people that couldn't get the time or wouldn't want to go to their boss and say 'this is...'. But I've just been really fortunate.

A: Cos I've found that quite hard to bring up at interview, well I didn't I don't think.

E: No. I don't think I did.

A: Well I might have done I'm not sure. But if they'd have turned round and said 'no sorry, you can't go' I wouldn't have been able to come.

B: Well that's like, when I first started the job I'm at now, I had to before my interview, I said 'look I won't be here on' can't remember what day it was back then, I think it was Wednesday afternoons or something, and I said, but that's the thing if I take this job I won't be able to be here, but so they still took me on anyway. I never told them what it was for. I just said 'look you know I won't be here from so-and-so'. So I was lucky from the beginning actually.

E: I did actually say to the headmaster, but I said this is what I'm going to, I told him 'look it's really important otherwise I wouldn't go'. But the evening would be much easier especially with the children.

B: If it was in the evening definitely

E: Definitely
314. B: Cos then you'd never have to have things to make ermm..

315. A: Yeah.

316. E: Wouldn't have to have an afternoon off every week

317. A: The you'd be able to come every week wouldn't you, cos I can't come every week, well I could but I don't like taking time

318. E: Yeah yeah that's what makes it difficult divvying up your weeks and he goes well I've got to go and take the car here or you've got to he's understanding most of the time. I feel bad sometimes

319. B: I'm fortunate I lucky because I work in the *** ***** therefore things are, things are quite good. I mean most works have been - I've been going like every week for I don't know how many years now,

320. E: Do you find it difficult to come cos you work?

321. A: I think they'd be alright, I just feel awkward asking for time off all the time. I mean they've arranged my hours so I can get this extra day off on a *** so that's ok, but um yeah and you don't have to make the time up, but I just keep feeling bad for asking for more time off and just cos it's a new job and that. I think they'd be alright, but..

322. E: It is hard asking.

323. S: So perhaps one thing that could be changed is thinking about more flexible

324. A: Yeah

325. S: hours or ...Does anyone else agree that's something they would like to see [pause] or anyone else disagree?

326. [pause]

327. E: If there were more people, I'd quite like other people with bulimia to be included in the group. Cos I think you know I know those feelings very closely relating, but

328. K: I think that goes back to I think it was your point C right at the start when we were talking about meeting other people.

329. C: Umm maybe

330. K: I think it's partly being able to socialise again, but perhaps also to feel that there are other people who understand.

331. E: Umm

332. [long pause]

333. K: We were talking a bit about what you think is important in terms of staff and perhaps by staff also thinking about NHS management you know service, the way that services are set up. What do you think is your impression having been around here for a while or being in other services perhaps generally, what do you think are the priorities of the people that run services? Do you think it's different from what goes on in your minds or is it the same?

334. B: You'd hope the priority is the patient and it's they're the important thing they're wanting that patient to get better.
I've always felt it is!

Yeah I think it is.

Confidentiality, support

The patient, yeah definitely, you wouldn't want it to be about numbers or things like that

No.

Obviously important you want that impression, you don't want to get that impression that you are 'just another one and then out the door' kind of thing. You want to feel like you're a person.

I think you get that in inpatient care

more. Umm you are a statistic and helping out their success rate.

Yeah

Oh really?

Definitely, you're just another

another anorexic.

Um if you don't do well it's like you'll let them down rather than it being really about you know the individual and your aim is just to put the weight on.

Cos the meal sizes are huge aren't they, aren't they 3500 calorie diets I remember for the first two weeks I just ate all day - a big cooked breakfast and that took me til half ten when you have coffee and 2 biscuits til lunchtime when you've got another cooked meal and a heavy pudding and then you get a cheese sandwich and then an evening meal and a heavy pudding at night time, and then you get coffee and biscuits for dinner.

It's unrealistic

It's horrible. And there's people, I know people in there who might leave fat on food, because they don't eat it, like most people without eating disorders don't eat it,

No, they don't

but they get it brought back and they have to eat it. And a friend of mine was in and they gave her 23 potatoes on her plate and who eats 23 potatoes?! It's just stupid! So erm yeah.

So what do you think are the priorities then in those kind of inpatient settings? Those who've been. Obviously you've both had....

Well beds, I got the impression I had to gain 3 stone, well they gave me 8 weeks, but it took me 12 cos I couldn't cope with doing it that quick, but someone else

How much did you have to gain?

3 stone, I was 6 stone 5 up to 9 stone 7

In eight weeks.
359. A: Well it was supposed to be in eight weeks, but I was able to stay longer but they kept pressurising me to gain weight quicker or I'd get chucked out, but...

360. D: It's difficult one though isn't it

361. C: It is very difficult for the first

362. D: when you've got, you know you've got beds in short supply and people do actually need to gain the weight quicker or they'll die half the time

363. A: Yeah

364. C: yeah it's really difficult to say

365. D: It's difficult where the balance lies isn't it, because they need that amount of calories to build them up. But if you give them that sort of food, or are you going give em that in like lettuce leaves or something, they're going to munching all day sort of thing, so I don't know where the balance quite lies.

366. C: It'll be a while won't it

367. A: I'd have thought a normal diet would. Cos most people when you get them off [inaudible]

368. D: But how long are they going to be there! You know you've got to have I can't remember what the ratio is but you've got to have like a normal diet plus another half or something to gain weight or something. I don't know what it is.

369. C: I think there need to be more steps. I know it is limited, there are more than there used to be, but there's still not enough, you know because I think going somewhere where you've got 16/17 patients that's not going to be... You need smaller manageable groups, but enough of, you know because of the fact that there is a lot of people who suffer from eating disorders. There's a lack of. In an ideal world we'd have you know all English people and, but it's not like that. I guess you've got to put those things into the equation.

370. S: Thinking about, I was just picking up on something about managers of services, do you think they prioritise services for people with eating disorders. Do you think that's a group who's high on their agenda or...

371. C: No! God no.

372. A: I don't know if it's seen as like because it's our choice not to eat isn't it

373. C: It's still a bit like that - they still think we're attached to it

374. [mutterings]

375. K: I was a bit intrigued by something you said about something about inpatient experience and it sounds like there lots more numbers, numbers happening and people coming and going, and you mentioned small and manageable groups. I was wondering what people's experience was of having taken up services in different kinds of I suppose in wards there's going to be how many people?

376. B: 16/17

377. K: And whether it's different if there are smaller groups and whether it's better or whether what people or worse?

378. C: I think that, I think smaller groups, but not too small though. You don't want to go somewhere and be - I've also been in an adolescent unit where there were sort of 3 eating disorders patients
among 8 general you know and that's not useful either cos there's not enough of you. but I think sort of 8 is enough people, but it's manageable and you know, you get the staff for that..

379. K: umm. Is that the same for other people?

380. A: I had a small group when I was in a unit [inaudible] and all with eating disorders and that was quite good.

381. K: Which is what C was saying about having the right number of people, and you think that worked?

382. A: I think that they reckon overall for the general groups about 8's about right.

383. C: But again it's [inaudible] ideally they would have 8, but they've got to accommodate 10 you know. And you quickly..

384. E: As you said, before 'in an ideal world' [laughs]

385. S: Coming back to thinking about - I think you've been making notes K - about what the most important factors identified in your ideal service were, to what extent do you feel - I don't know if we could summarise there the main - to what extent do you think that the [name of the service] is actually meeting those?

386. K: Ok, so the big thing is the individual being treated like an individual yeah and everybody changes in different ways and in a different order yeah. It's not just about weight gain, so it's about providing lots of other support on the other issues that are around food. Fair point. Support for relatives, support for mums. Um supporting people's individual responsibility for change rather than defining what the change markers are, so it's not just about gaining weight it's about having people chose what they need to do. Umm convenience of time, that was another one. Therapy skills backing things um don't know education groups. Something about staff education there wasn't there - actually educating and networking in with GPs and other people so that actually people can yeah turn up in a more equal way rather than replying on whether the GP has found out or not. have I missed anything else? Umm small manageable groups that was the other one! Umm have I covered all of that? Anything else, have I missed something vital?

387. D: I think in letting people set their own goals, but also on the flipside of that, is for them to sort of be challenged a bit. Cos you can sort of

388. A: Yeah drop your...

389. B: Plod along and not really..

390. D: You can! You can also be so entrenched in your eating disorder that that seems like the be all and end all. Whereas you need someone who's a bit more logical to sort of say 'hang on you're just sort of saying that to feed into the disorder'.

391. S: Do you think that balance is kind of right here, or do you think it tips too much into the sort of responsibility or..?

392. D: Obviously it depends on the therapist, I mean I've had various, but generally on the whole that is about right

393. [agreement]

394. D: The fact that you're accepted, cos I mean sometimes in the inpatient you get told 'that's eating disorder talk' whereas, in fact I've felt like that before the eating disorder, but that isn't accepted, sort of thing, but it's a hard, hard balance to strike. It's not til you've sort of built up with a person that you really sort of know whether they are conning you or not.

395. K: We're running out of time as well, so we need to be thinking about
396. S: winding things up. Is there anything else anybody wanted to say in terms of whether they think we're meeting those standards here?

397. A: It's quite a positive place I find. You don't sit around and I mean you have weeks where you really bad time and talk about your eating and stuff, but on the whole it tends to be talking about other issues rather than all sitting around and saying what we've had for lunch and 'gosh I had 2000 calories'

398. E: What colour swimming trunks you're going to buy.

399. A: Cos some of it's you can end up with battling with one's [inaudible] and that isn't much help really.

400. B: That's what's so good, especially about the group, it doesn't have to necessarily be things that are directly related to the eating disorder but so many different things can trigger things that you can talk about anything and it may affect it, it may not, but it helps.

401. S: Ok what might be quite useful, is if we all go round the group and each say one thing we'd either like to either continue, alter or begin that we feel the service here is doing at the moment. So if you want to continue something that you like that's happening now that you'd like to continue, something you'd like to change that's happening now, but you'd like to see done in a different way, or something you'd like to begin that isn't happening now.

402. [pause]

403. S: With the look A's giving me, shall we start with E?

404. A: Sorry [laughs]!

405. K: We'll start with you then Ay!

406. E: That's really hard. [pause] I think to continue with the supportive environment we have within the group so. It's almost like a gentle persuasive rather than anything that's too harsh or too difficult and I think if it was we wouldn't, we already have so many things in our lives already, for you to have to face something really harsh every week, would be put off it. I feel it's something we all want to come to and benefit hugely by. yeah, just, you know, support as a mother I would appreciate.

407. D: I agree with what E was saying really. I think at the moment it's good that there's been stability both with staff and with patients really. I've found that very helpful.

408. C: I don't come to any groups. I just have individual therapy [inaudible] I have a lot of issues with that, but it's something I'd like to work towards.

409. E: We are very nice!

410. [laughter]

411. C: because I think it would be useful, and it would help I don't know, anyway.

412. K: That ties in with the idea of actually connecting with people doesn't it? Actually having that sense of um belonging, but like A was saying in a way that's going to be helpful that's not just going to be about how many potatoes you've had

413. C: I can see the benefits of it, but it's sort s of opting in to do it I think and then if it's going to help
139

414. B: It's extremely daunting the first time... the first time you go into a group because you know
you walk in and you're like 'Oh my God I've got all these issues' and you know there's people you
don't know and trying to

415. E: Frightening

416. B: Oh extremely frightening - I remember like first going into a group and for the first few weeks
you know I sat and I listened you know you build up feelings about the people around you you
ger to know people and after a while you gradually do get the courage you know to input more,
but it does take time. I do remember the first time - I was like 'ahh'

417. E: I felt sick

418. B: oh my goodness I was so scared you sort of - 'what are these people thinking about me' but
now it's just such an important such an important part of my life. It what gets me through every
single week

419. S: So is that something you think you'd like to continue.

420. B: Definitely. I think it's very important, extremely important and you've got therapy that works
for each individual.

421. E: I like it being called a transition group it feels like we're moving on

422. B: Yeah!

423. E: Or something.

424. B: Cos the transition group was very very daunting. I don't know if anyone remembers, but the
group we were in before this one. It was quite a scary thought and like the ideas you have about
a group. Honestly I was really really nervous. I was like 'oh my goodness' - I thought we were like
going to be made to gain weight.

425. E: To move on quickly.

426. B: We thought we were going to have to talk about food every week and it was really surprising,
we were so scared honestly we were honestly about coming to this group because we didn't
know what it was going to be like. We were like 'oh my God!' Honestly it was really nerve-
wracking cos there were going to be new people

427. A: There was only me in the group wasn't there?

428. B: In the very beginning

429. [lots of talk]

430. B: And then in the end in the first few weeks there was me and D and *** and A. So we knew
each other. We just kind of.

431. K: But actually the idea that it's pacing the transition isn't it? It's something about having that message
isn't it that actually you are moving on, but not to other people's ideas.

432. B: Yeah not being forced into this. I know you are I just do remember being so anxious about this
group when ***** he said that he wasn't going to do it anymore we were we were we were
quite cross actually, weren't we? We felt, that's one thing you do have to be really careful of,
about is we did feel, I admit I felt a bit let down that he was like he's going to do all this new stuff
at the university and what about us kind of thing?
433. E: [laughs]

434. B: So I think if you're going to do things like that you have to do them gradually. And you have to be very careful about it because people become reliant and change is very, very hard. So you do stability is extremely important. Extremely important that you don't have stuff going in and out, in and out all the time.

435. E: Poor K's sitting there [laughs]

436. K: I've got it all down.

437. B: It does take a long time to like deal with trust with someone

438. C: You can't go anywhere

439. B: Yeah you're not allowed to go anywhere.

440. [laughter]

441. A: I miss the dietician coming into the group. the dietician group actually I don't know if we've had one in this one. In the old transition group back in the old days when I was young.

442. K: What about the service generally?

443. A: What about the service generally?

444. K: In terms of... What was the question, there was something you'd change

445. S: something you'd alter and something you'd begin

446. A: Don't know.

447. K: It might be worthwhile thinking about that later

448. B: Just trying to pick one thing's difficult cos everything's important about a service, so just to pick one thing out and say that's the most important I don't think you really can. It's all the little things that make a service what it is.

449. E: Security, support, confidentiality

450. B: Yeah it's huge, everything is important.

451. A: I can't think of anything I'd stop.

452. ?: No.

453. S: Ok is there anything we've talked, we've not talked about today that we should have done.

454. [long pause]

455. K: You'll be driving out of here and you'll remember

456. B: We'll be on the phone

457. S: Lots of answerphone messages when we come in tomorrow 'we've remembered this!'
APPENDIX V: TRANSCRIPTION OF FOCUS GROUP 2

1. S: Well as I've said my name's S and I'm a trainee Clinical Psychologist and I'm hoping today really just to get some information - because I know very little about the day programme it will be really interesting to hear people's experiences of that.

2. F: Umm, my name's F and I've been here since October

3. S: Right

4. F: And I'm hoping to be finished with the actual day programme by the beginning of June at the end of June

5. S: Right

6. F: !!!!!/ 

7. G: And I'm G !!!!!!!! And I feel fine about being here

8. S: Right, excellent

9. [long pause while K enters room]

10. S: K, How are you feeling about being here?

11. K: I'm looking forward to it.

12. [laughter]

13. K: I'm really looking forward to this!

14. S: Ok shall we get started then? I've got a whole list of questions to go through, but if people want to go a bit off track or ???????, but the first thing I wanted to ask you was thinking back to before you started - I know you both started at quite different times - what were your kind of hopes before you started here?

15. G: Um do you want to go first? [laughs]

16. K: I'm just going to be taking a couple of notes just to structure it for the purposes of the the transcription yeah?

17. G: Yeah that's fine. Um I hoped to get some guidance um nutritional guidance about what I should be doing. Reassurance that I wasn't completely crazy - that there were other people like I am and that I could be helped. Umm and support.

18. F: I think my major thing was um reassurance. The thought of eating the foods, the thought of doing the things which I knew were normal was too big a deal. It was like something I thought was too big it was like really really scary so I just I just wanted I just really wanted it for reassurance to be able do it really. The back-up, the support, definitely.

19. S: And did you, did either of you have any fears about coming here?

20. G: Loads!

21. F: Oh yes!

22. [laughter]
23. G: I think I had every fear! I thought I'd be different to everybody else. I thought I'd be huge compared to everybody else. I thought I thought I couldn't do it. I thought I wouldn't get better. I thought that everyone would think I was strange.

24. F: I was just worried because I knew it meant that I had to change the things....It was like letting go that was the hardest thing. I was worried that the amount of food was going to make me like really big and I was worried that...I just liked parts of what I was doing and I didn't want to let them go and I knew that it would make me let them go that was the biggest scare was just thinking I can't go for this run all the time or I can't misuse laxatives that sort of thing.

25. G: I think also like someone checking up on you like particularly with food logs and stuff is quite scary to have to write down what you eat and stuff

26. S: Was that still quite scary when you started or

27. G: Yeah

28. S: was it kind of what you expected?

29. G: Umm not as not as scary once I started

30. F: I think it was the opposite for me - I wanted that check because I just felt so I couldn't do it myself that's what I came in for. I wanted someone to just do it for me, to take away the sense of responsibility.

31. S: Ok, so that leads me quite nicely onto my next question, about what the role of the [name of service] is in your eyes?

32. F: Education.

33. G: Um yeah reassurance and education

34. F: Yeah that's true

35. G: And like, space to be able to challenge yourself. It's like, once you settle in, you feel quite safe and you're able to do things that you wouldn't normally do.

36. F: Yeah, you get....Reassurance is definitely the main one because food's just so scary. And and yeah just the educational aspects as well. Cos you have ideas about you know you learn about what you're doing you learn about your behaviour so it begins to make sense again. So it doesn't get to the stage where it's just all so confusing and you know what you're doing is wrong and it just sort of makes sense again.

37. G: It's um consistency as well

38. F: Umm.

39. G: It was kind of I knew what to expect and basically I knew the pattern of each day and what was going to happen and obviously things change from time to time and that was difficult and scary, but generally it was quite ? ? ?

40. S: Ok, so if we were to ask you two to set up your own eating disorders service to any model you like - tricky one then just redesign the NHS for us - what would you what do you think you'd start by doing?

41. [pause]

42. F: To change it umm?
43. S: If you were to build up a service from scratch.

44. K: If you had carte blanche if you could do ... based on your experience yeah what's worked and not worked for you... what would you... it's a good question isn't it?

45. S: A difficult one.

46. G: I'd like to make assessment easier. Umm and try and pick up eating disorders earlier, like in schools and stuff.

47. S: Right - how do you think you'd you go about doing that?

48. G: I guess more education for teachers that are in like quite an influential role. Umm cos certainly I think teachers should have noticed something was going on with me, particularly at boarding school. Um and I think parents as well I think it would just help if they were.....to raise awareness.

49. F: Umm I'd sort of want to look in, especially in the initial stages in the first like three months some sort of support for like after we're leaving. I don't know if it's worth having longer days in the first initial months because I know I've got tremendous support and I really at the beginning I don't how much I could have done on my own. I don't know if I'd have done it as well as I could have done if I didn't have that support. Because you know literally I'd come home from here and you want to....there's all these urges to want to run, to want to get rid of the food to not eat anything else for the rest of the day and without that support I don't know if I'd have been able to got through those first couple of months.

50. S: Right, so you think for perhaps people who may not have that level of support?

51. F: Yeah the initial couple of months I think it's um yeah support. I don't know if it's worth having a longer programme, or some sort of evening session or... I don't know. I'm not sure.

52. G: I kind of agree with that, but also I think that it's been an important thing. You'll have to take responsibility for yourself in the afternoon sometime

53. F: Yeah I know

54. G: and that's going to make it easier ??????.

55. F: Yeah, yeah.

56. G: I think there's the carer's sort of thing like my dad's only been a couple of times but it's really helped him and I think more things like that would be helpful.

57. S: Right. Could you tell us a little more about that, what sorts of 'more' things?

58. G: Ummm just I think when I started I didn't really feel able to talk to him about what was going on. Umm about even what I was doing here and I think that perhaps if he had been involved in, maybe, just told what was going on then that might have helped.

59. F: I've been going to family therapy and I think it's nice that that's introduced once a month or whatever and that's been quite good. You know, even if you don't necessarily have these family problems and it's just for support um it's just a good forum I think.

60. [pause]

61. K: Shall I just recap on what's been said so far? To keep it in... it's quite interesting actually. So, picking up eating disorders earlier and assessments earlier, so education for teachers, perhaps parents as well. Umm in the initial stages - F you were pointing out you had good support in the afternoon and evening and without that you thought......
62. F: Yeah, yeah.

63. K: and not our that's not a service that's offered here. But on the other hand the flipside of that is about responsibility-taking and the benefit of think ??????????? I don't know if you want to add to that at all?

64. F: Maybe do it in stages just like the first couple of ...unless it depends on each case. But I know (I don't know if I should mention her name) but there was another girl here who was quite young and found it hard coping in the afternoons and evenings, just as I went to the first sort of, just a slow development of progress. [pause] So it introduces it in stages then also on the other hand when you get to that stage you do feel like you've achieved something when like you get to the stage where you get to cut down your previous it's like carrying on, and then you build up and you feel like you're achieving more earlier on when you get past the first month or two then you know you start to spend.... some people may take like years, but it's nice to have that sort of... it might help it go quicker.

65. K: Mmm.

66. G: I guess weekends are really long as well and things like Bank Holiday weekends feel really long! I think if I was doing it then I'd probably have some kind of support.

67. K: So, assessment earlier, education for people, support issues in the evening, umm the weekend issue, the graded stages idea to work between responsibility and independence isn't it? Umm, relatives group like family therapy

68. F: Oh yeah

69. G: Yeah

70. K: And that's something about including, that's about including other people?

71. F: Yeah it something it takes the focus away from you. it's always the thing with eating disorders you get very sort of focused on yourself and sometimes it's hard to you know... you forget about other people. For me it's how things are normal as well and to have normality again I don't know I just think it brings in other people and it sort of widens it a bit and encourages you to sort of think about ??????. But it's not just all about you. it's not just you and your family's the problem or you know it gets you to think about other members of the family and how you interplay with them.

72. [pause]

73. S: Sorry, I was just going to say, moving onto picking up something you were saying G about the assessment process being made easier? Is that do you think just for early detection or is it the process as well?

74. G: Obviously I guess the process there was quite a lot of like repeating myself and stuff and I felt hat I had to tell my story like six times over and you know it was hard enough to talk about it, let alone to talk about it six times over, but umm. With so many different people and not feeling like I was getting anywhere and not knowing where I was going and why I was having to tell all of these people.

75. [long pause]

76. S: Ok, moving onto the next question - I guess it kind of encompasses some of the things we've already discussed - but um, what do you think the most important things, if you kind of had to list some of the most important things in an eating disorders service, what would they be?

77. [pause]
78. G: Individual therapy.

79. F: Yeah [pause] Education as well. There are things you know you do or that you think or behaviour that sort of thing um and that sort of thing I know a lot of like schema-work that sort of thing understanding then it makes sense and you can work on it and you know what you're doing and you can see patterns that sort of thing. I've found education to be really interesting. Just understanding about yourself and how can you stop something that feels so right you know when you start to understand a bit more it's...I don't know what you think about that?

80. G: Umm. You can't change anything til you understand

81. F: Yeah.

82. G: what it is kind of thing. [pause] And the body image group has been useful, really useful.

83. F: I think um one thing that's quite common with eating disorders, is it's that um it's quite hard to accept a womanly figure. I mean each one of us in our own way was trying to get rid of any possible curve, shape anything - whatever the reasons behind it. And emphasis on you know the what woman's body that sort of thing - um obviously you have men in here as well so that would change, but that's quite important I think. And that's only really started to come up for me recently but yeah sort of changing shapes and bodies and that sort of thing.

84. G: I think it's really important also like when we get weighed and stuff we can talk to whoever's weighing us and talk about it like immediately

85. F: Yeah

86. G: It's not just left you're not just weighed and then 'goodbye' that is really important because in other settings that hasn't happened

87. F: And I think um the log sheets at the beginning for food and stuff like that - I do think that's important and um. I mean not as important as some of these other things that. I don't know it's err...I know I was kind of naive at the beginning I thought everybody did it and no one had to do it so I was so strict with myself. But when you know that no one else does it you think 'oh I don't have to do this you know' and it is easier to cut corners and like I don't know I think I was probably naive in thinking that *** was gospel and I had to do what *** said and that sort of thing. But on the other hand if it's going to work you need to stick to what she does it is worth having these things that you know what you should be doing and being checked up a bit which is you know it has to be done but I think it is worth being done. Because at the end of the day that's the initial struggle before you know what's going on it's just you get that feeling and you can't think rationally.

88. S: Mmm. [pause] Any other key, key points?

89. F: I think involvement with like other services that we've been in before like with the CMHT and stuff, I think it's really important that everyone communicates.

90. S: Ok, we've got quite a big list and I'd like to come back to that in a minute or two if that's ok? But next I was wondering what you think the staff think are the most important things in an eating disorders service?

91. [long pause]

92. G: [laughs] I don't know!

93. F: I'd say maybe consistency. Umm you know they so they were comfortable so that it say how they met umm consistency I guess.
94. G: I think being aware of everyone’s individual needs as well.

95. F: Yeah we’re all very different.

96. K: Do you think we are though? Is that something you think is important or do you think that’s what the staff do or do you think they should do it more?

97. G: I think the staff do. Yeah.

98. K: Right.

99. [long pause]

100. F: Yeah the staff do. There are times when you think ‘oh so-and-so’s not doing that?’ or ‘where is that person there?’. And the staff will say you know you need to understand people and appreciate their involvement some days want to talk more/not want to talk more that sort of thing, you know people are in different stages ?????????

101. G: I think that’s about keeping normality as well, cos you don’t always want to speak.


103. S: What other things do you think the staff think are important? I suppose I was quite restrictive before because I said the staff ‘here’, but I’m wondering if staff in other services, other eating disorders services and perhaps people like managers, who aren’t necessarily based here but are also thinking about coordinating the service?

104. F: I think the Wednesday reviews that are here are excellent. I was really amazed when I didn’t know they do that. It seems quite logical but it’s just it’s really nice to know that they discuss you and have these meetings and all come together. I think that’s really important and I think that would be important for the staff.

105. [long pause]

106. G: I’d say structure as well. [pause] I think my…..the CMHT were really keen that I have a structure that I’m actually forced to do

107. S: Anything else you want to add to that one? [pause] Ok, going back to the list we had before I suppose the staff list as well on areas that you think are most important. Perhaps K could recap on those but just keeping this question in mind, just thinking whether the [name of service] is actually meeting those those criteria?

108. K: Phew right. So, how far back do you want me to go?

109. S: Go from the beginning - shall we make sure we cover everything?

110. K: I’ll have memorised this! Ok so there’s um education, reassurance, consistency, um assessment being quicker and less repetitive, yeah?

111. G: Uhm. Almost supportive I think it needs to be - supportive that you’re coming forward and asking for help.

112. K: That’s an interesting way of looking at it, isn’t it?

113. S: Umm.
114. K: Support for afternoons and evenings at the start and maybe the idea of a graded levels of support, um including ideas about taking responsibility, relatives group, family therapy. And then there's individual therapy, education, understanding - helping it make sense, the groups: body image group, um, having structure and filling in the log sheets actually doing the written work that goes with the programme, communication between services and those are things that are important to you. And for staff, staff um, find consistency important, are aware of individual needs and I've put individual differences just more like normal yeah? And communicate with each other on Wednesdays.

115. S: Ok, so now remember that whole list! To what extent do you think the [name of service] it meeting those things that are important?

116. F: I think very well.....very well.

117. G: Can I add something to the list?

118. S: Yeah.


120. G: That you can't fail - no matter what goes wrong or what happens there's um, it's always, there's always be a way around it

121. S: Is that something you think is important or something that's actually happening here?

122. G: Umm I think it's important and it's happening.

123. S: Right.

124. [pause]

125. K: What would could we be doing more of within the, in terms of the things that have worked for you or could work for you are there things that you thought 'actually that's a really good idea' every service being what it is we're all thinking about changing and adding things or are there things that we could be doing slightly differently within that?

126. G: Sometimes, umm although the body group has been really helpful sometimes it would be useful to have individual work on that. Because it's quite daunting speaking within a group sometimes, even as much as you may trust everyone particularly if it's a large group, we've been really lucky we've had a small group for a while now but when it was larger it was really hard to do anything really very constructive.

127. K: Umm.

128. S: And do you think in general that smaller groups are perhaps more helpful?

129. G: For body image yeah. I think that for psycho like for psychoeducation it's useful when you've got loads of opinions, but it's also difficult to talk in a big group. But for body image definitely I could, some individual work would be useful.

130. K: It's an interesting thought that different groups have different needs really or....

131. G: Umm.

132. K: Is there anything else?

133. [inaudible]
134. F: Ummm I did enjoy having one group or whatever it is that's not heavy-going. Like we used to do tai chi but that was people didn't like tai chi that much, but some sort of group where you've got the to bring together so you have fun a bit as a group as well. I do think it's a good idea having a lot of you know the time a lot of you do have the time to relax, cos a lot of people with eating disorders are constantly on the go, it's nice to make you slow down, but I think it's important to have that sort of bonding session as well in some sort of activity, whether it's just sort of an hour of just like I don't know oh I can't think some artistic thing - just something which you can all enjoy and you can share an interest in and it's not a stressful group or something.

135. K: Umm interesting point - it's acknowledging that really actually the groups are quite heavy

136. F: Yeah

137. G: Yeah

138. K: And all of them are challenging.

139. F: It also gives people the chance to be themselves - some people feel uncomfortable in front of food, some people feel uncomfortable in different you know different settings like body image and this is just kind of it's like normal doing something normal together.

140. G: I think sometimes I would find it useful if we stayed for longer after lunch as well. Umm I mean sometimes it feels as though half past one comes and we just we just go. And I feel you can go and talk to someone, but sometimes it's quite hard cos you're feeling bad to like approach someone and maybe it would be better if we were actually given the option to stay a little bit longer. Or even if everybody stayed like an extra 15 minutes or something.

141. F: I know at the beginning I really need that when I got home someone to be at home just for a chat or . I wish !!!! There is that feeling ..... There's always someone you can talk to but after a meal you know people look round and maybe a couple of people need to speak to someone and you feel a bit bad to say 'oh you're really busy but I need you' you know that there is someone there, but it is it is hard. Especially when it does get easier for other people though I know people like me I leave straight away now I go off and do this, this and this, and it can be quite I know perhaps some people find that quite awkward.

142. S: Umm. So it sounds as thought there are a few areas where improvements could be made and it sounds as thought people have some quite practical ideas about how they could be made, which is really useful to hear I think.

143. K: Ummm really interesting. Thoughts. It's not a long time is it between - when do you finish lunch?

144. G: About a quarter past one

145. F: Yeah quarter past one and we're pretty much gone aren't we?

146. G: Yeah half past one we're gone.

147. F: [inaudible] I think on the sheet it said the 'food and feelings group' so I was sort of hanging around for the first like few weeks thinking 'where's this food and feelings group?' and it's not there. Can be...especially for the first sort of initial couple of months I think especially if you're not used to eating anything and suddenly you have these meals and it's quite a big deal and it does come up they don't there's no messing around you're straight in which is how it should be.

148. [pause]

149. F: The other thing I'd say on the practical front is umm I think it is important to show some of the dangers that we doing to our bodies at the beginning you know not just as a scare tactics, but as reality as well because umm ****'s quite good at showing us like with food **** unfortunately
we haven't had too many group things sort of about calcium and stuff. But um I know someone
the other day was like 'oh is bulimia going to really affect my chances to have children' we should
have been like aware of that you know it would be important to have that awareness. And if
you're anorexic what is it doing to your insides? Just so you can, how can you supposed to like
love your body if you don't really know much about what you're doing to it. And people don't
realise the effects of it and things like osteoporosis and stuff like that umm it's really umm people
might say to you 'oh you'll get osteoporosis' but ok you know it really doesn't mean anything. It
would be really nice to have some sort of education group about practical things like this is why
you need a bit of fat in and that sort of basic stuff and maybe just one or two groups just
somewhere around not even like a regular thing.

150.S: And do you think that when you started you'd be ready for that right at the beginning. I'm just
wondering if that would have been quite difficult perhaps...

151.F: Yeah, yeah maybe sort of yeah. Maybe initially that would be a bit overpowering wouldn't it?
But I know cos my mum sort of helped me, showing me about bulimia and just your teeth and
that was good yeah and I found that quite useful just to sort of try and care for my body a bit
more and it still I would still like to know a bit more. Why you're looking after your body what
you can appreciate. But yeah as you said probably would be a bit later may be a bit overwhelming.

152.S: Ok, well I'm probably the novice here because I don't know much about the day programme about
what sorts of thing you have there at the moment. Obviously there's the body image group and the
psychoeducation group, but is there anything that isn't on the programme that you think you'd like to see
on?

153.F: Probably just that group. You know we tried to call it a support group, but even that gets a bit
you know 'ughh', just like another session and it was like kind of 'ughh' because it's unstructured
you know it's even more. But some sort of bonding session I think, or some sort of away from
the focus, seeing people as people a bit more, realising we do have characters away from that
bit more, which might help people as well. And maybe some sort of session like maybe an
optional session around education I don't know whether it's worth it or even if you do it as like
an evening session or something where the speaker comes in to talk or something like that or
whether you know someone wouldn't mind staying at for like an hour in the evening at 5 O'clock
or something to have a session about what it does to your some dangers and stuff. I think that
would be quite interesting. It does make you think especially when you have a weak moment.
You know it is anything way which keeps it all in your head you know, Cos none of us you know,
one of us want to have children and especially in our group there are people who are on on
that way and you do, it's nice to learn about things like that. I don't know if that's something that
should happen in schools a bit more really I think. You don't realise what you're doing and
suddenly you get these problems later on and 'oh if I'd have known' you look like [inaudiable]. It's
like doing yoga to prevent being stiff when you're old it's just sort of you know things that you
can do.

154.K: I'm quite interested in the idea of the groups and that was a good point to make about lightening up a
little bit yeah? What were your thoughts on that G?

155.G: Yeah it'll be really it's really nice to have groups where we can just sort of laugh a bit. We do
get very serious and actually sometimes I go away from here thinking 'I'm so tired I've been
working so hard all morning'. And yeah it is hard work isn't it?

156.F: It can be yeah. And just and sometimes when you don't have it, it's nice to have a bit of space
on your own, but then you sort of you know I think it would be nice it would be nice to have
that really. It would be nice to have something on the creative side or.

157.G: Mmm.

158.F: Have some sort of.....I mean definitely not anything too you know maybe tai chi was a bit too
much maybe just something a bit more relaxed or like you know I don't know really.
159. G: It will be more normal.

160. F: Yeah

161. G: We've built up such strong relationships with each other based on the fact we're sharing so much, I think to have

162. F: Yeah

163. G: something a bit lighter would really help with that

164. F: Yeah I think so.

165. S: One thing that's just occurred to me is to what extent would you want the to be staff involved in that?

166. F: I think umm I think it would be I don't know I think umm **** and **** would be I don't know. I think it's probably ?????. What do you think about that?

167. G: Yeah umm we're not very good at organising things ourselves are we?

168. [laughter]

169. F: Yeah I guess because people's motivation at different times


171. F: And people have bad days and stuff. I think it is probably worth having I think we'd need *** there at least. Don't you think?

172. G: Yeah

173. S: I think there was something you wrote down about the assessment being more supportive K that you wanted to come back to?

174. K: Yes. [pause] I think it was G you were saying about the assessments being supportive that you're actually moving forward would help. And both of you what your experiences were of assessment actually other than you were mentioning...

175. G: I felt like I was being judged. I felt so embarrassed and awful. And to have to go through that more than once it's not fair.

176. F: I agree with you the repeating and it does get really difficult, keep meeting different people and talking. And I think especially in my circumstance I didn't really have a set issue that I knew was the problem and umm I always thought mine were pretty trivial issues and not really worthy of eating disorders - I just thought I was being stupid. So to have to sort of be confronted by someone who's like 'so why are you doing this?' and well 'to be honest with you I really don't know' and it's like 'well what's your big issue?' and for me it's like 'well umm haven't really got one
you know' and it sort of makes you think I don't need to be here, this is fine you know, it's for people with much more serious circumstances. And it's quite difficult to keep having to go over because it reinforces the fact that I felt it was really trivial. Not so much here cos I thought the whole - I had *** and *** it was quite an intense session but that was fine, obviously it was really scary and horrible, but I thought that was a good a good intro into it. It was more before when you go through your GP and then you go to the CMHT and I think you did that twice and I ended up seeing two different people and then I came here and I know there was something like **** was actually ill that time and I'd met **** and felt comfortable and it was that is that is quite hard to be confronted by different people you know. But I think once it was here and all like got onto that first assessment here really then it all seemed ok to me. I mean obviously the [inaudible] was horrible.

179. G: Yeah.

180. F: But there was that consistency, there was that sort of umm you know you felt like there was they put that support I remember there was that support there was that first initial day or something that you plan and then you have another two weeks before you come in for the community meeting and I like that there was like structure and I thought that was really needed in a gentle way. And you'll be prepared and you have the date and I think it's really important to know exactly what's going to happen and what's going on. And that's what's difficult for just before you come here, it's so many different people and you don't know where you're going and if I don't get on what's going to happen and you have this date in your calendar which says you're going in now, but am I, am I that sort of thing?

181. K: I think that's just really interesting isn't it about how the way that people get here, So you both went through GP...

182. G: CMHT

183. K: CMHT and then you got here?

184. G: Yeah


186. G: Yeah

187. K: What would you do if you know magic wand you know, tomorrow you change the assessment process what in an ideal world you know what would happen?

188. G: I'd skip the CMHT

189. F: Yeah I think that.

190. G: If you need the CMHT involved then I'd do that after

191. F: Yeah definitely definitely cut out the CMHT.

192. G: It wouldn't

193. F: The only thing that I think it would be good for is if you really can't be seen by here for six months by you know for security reasons or whatever. Other than that it's just a real....it almost puts, it can knock you to come here I think in a way because it's it's just like 'I can't go through that again' and you have that meeting and it's not as short it's not as structured cos it's just a meeting with someone - it's just an any old person you're talking to whereas here you know you're going to be going into a programme it's got a follow-up, whereas that's just a nothing you think well if it doesn't go beyond that what's you know it just seems like a......
194. G: They weren't very aware of what would happen

195. F: No

196. G: after they saw me either.

197. F: Yeah. They didn't really

198. G: No.

199. F: But here it felt like they knew what was right for you and they recognised some sort of condition or something I don't know. You weren't odd like you belong there whereas here you know at the CMHT you go in with a problem 'oh this is a problem case, what shall we do with this problem case?'. I would agree I don't know what the use of that first [inaudible]

200. K: That's really interesting feedback, but you're quite clear that it was horrible?

201. G: Yeah!


203. G: They didn't know what they were talking about. They didn't understand.

204. F: No. And it felt more like something it felt more like that they were just trying to keep you that no one's really ready, it wasn't organised or wasn't set up and they were just trying to fob you off with something - it's like we're here'. Which I'm sure it's not, but that's just the impression that you get that you don't know what's going on and you get the feeling that and obviously you know you hear about waiting lists and stuff and you wonder if it's a bit sort of like a....

205. G: I think if that step does have to happen then the CMHT needs to be given more information. Umm the person doing the ....it would have helped if I'd just been given even a leaflet or anything. Just something 'oh yeah we recognise what's what's happening, you know we are taking you seriously'.

206. F: Here's some support groups in the local area

207. G: Yeah

208. F: or even in the local area

209. G: Yeah here's some help in the meantime, should you chose to

210. F: Yeah

211. S: I suppose going back to the step before that, how did you find your GPs? Did you find that they knew where to send you or what the next step was?

212. F: I think my parents researched the steps for me. Initially when I first went ages ago, like years and years ago I saw my GP who was just like 'ok so are you anorexia and bulimic then?' 'eerrrr ummm!' and that was it was just like that was it he was really sort of ...... And then I saw another one and he said 'oh I'll tell you what I'll give you some anti-depressants, you're obviously depressed' oh ok not going to go down that route. So they both really scared me off and umm then I sort of went to the homeopathic route I saw somebody and that helped for a while but it you know it's like the symptom not the cause sort of thing it's taking the initial that was ok for a while but after that I just sort of went back into it and my parents researched when I was away and really ill umm into different places and found out about this place and then probably you have to go to your GP first. So I went to my GP and she wasn't there the normal lady I have, so I saw another lady who was absolutely lovely and she was just umm a supply lady, but she was really
really lovely, really understanding and um yeah really good and she sort of said 'oh look will you come and see me next week' and she saw me you know not even to discuss anything but just to sort of say 'I'm here and supporting you' but that was really nice so I had that and she made sure she saw me every week until I got through to the CMHT and that was really good. She used to sort of ask me about, she knew that I didn't get on with my parents she didn't really know that much about it, she'd just sort of say 'where are you living at the moment and is that working out for you?' she just sort of took an interest and just said 'look come and see me every week so you've got this routine'. I think that's really important isn't it when you really don't know what you're doing or where you're going it's just some sort of safe place isn't it or something like that and that was her for me.

213. G: Umm, they didn't take my eating disorders seriously. Because I had depression and I was self-harming as well, those things took priority and they they just said 'well we're not going to do anything about your eating disorder until it gets much much worse, you deal with it. We'll sort the other stuff so we'll deal with that first.' Yeah it was just a mess.

214. K: Did you just see the one GP?

215. G: No I saw probably three. Umm and they just said there's nothing they could do until it got worse.

216. F: Good incentive to get better then!

217. G: Yeah!

218. S: So perhaps then for each from the issue of thinking there might be a problem to getting here seems like a long long...

219. F: Yeah

220. S: Difficult and quite painful.

221. F: Yeah.

222. G: Particularly as you didn't even know it was going to work.

223. F: Once you are on the programme or you've just had that initial thing it's such a different feeling to like. I mean that's half the reason I think the time between when I got back in July and then starting the amount of decline was absolutely incredible. You know before that if I'd have gone in in July I'd have only, but some of the process then that was a really crucial time for me those three months.

224. [pause]

225. F: Cos you know that you're waiting there's no point you almost give up you almost want to make it worse to prove that you've got this eating disorder in a way. I had mine for quite a while, but it was never like at crucial BMI stage it was just basic eating disorder with a sort of low-ish BMI not anything on the critical line. And I think when it's like that it's quite hard cos it's like well what do you do - I know I've got this problem, but I'm not sort of this clinically, really clinically anorexic person and so it almost makes you want to get to prove you're that ill so then you can sort of get the help whereas sometimes you know help is needed a lot earlier on, but you know to the outsider you aren't, you're just a little bit slim,

226. S: Thinking about drawing things to a close, thinking about all the things we've discussed today, what do you think the most important thing is?

227. [long pause]
228. G: I think looking back it would have been the assessment process, but for now it's that I can't fail and.....and I think the thing that would help me most is the individual body image work.

229. K: Can I ask about the 'I can't fail thing'? Can you just explain that a bit more for us?

230. G: Umm. Just because umm I think that I've always been a perfectionist all my life and when I got ill suddenly I couldn't do anything and I felt like I'd failed at absolutely everything and to come to an environment where you actually constantly you're reassured that you're doing well and no matter what's going on you're doing well and you're trying you know and to be recognised for individual achievements and just little tiny steps that you make that you put down as insignificant, you know, but they're not. It's just been so important for them to be recognised. It's made me grow. [pause] I think it add to safety as well. I've been able to do some amazing things that I never dreamed could be possible.

231. F: I think a lot of the educational stuff - I think I've learnt a lot about myself. About behavioural, cognitive-behaviour, everything in general - it's just been really useful. umm support and err reassurance you can't explain what that means when you just when it's the scariest thing in the world to get there. Apart from that it's having the opportunity to come really, it's been so beneficial. Everything's so useful, yeah and wish more people knew about it could make use of it.

232. S: Is there anything we haven't talked about today that we should have done?

233. F: The only thing I'd like to mention is that it goes through, like obviously the groups are very challenging and that sort of thing, but it does sometimes concern me how umm it's all very safe and comfortable and I wonder sometimes if it's allowed to be too safe given the fact that if isn't quite that real drive it's so easy to just stay and keep going and you get into such routines and even like everything's real sort of I think if it can be it needs to keep coming that challenge and maybe if you've been there for a while. We've had some real challenges you know challenges I think challenges when you get to that when you've been here for a while and it is safe I think you need to have new challenges so like sometimes we have we'll bring in a cake for someone's birthday to shake things up a little bit maybe once a week you can't choose the exact thing on the menu or there's some other change to get out of that routine. There's so many challenges in the initial 4, 5, 6 months and then suddenly the challenges stop and you can do certain things, but then you have to cope with other challenges in your life all the time and there's no new challenges and it's all very safe and I think that's quite I think it's important to umm not forget the people who are have got up to past the critical bit and to keep working with them because it's still going in other areas.

234. S: Right is there anything else anybody wants to say, any questions or comments?
APPENDIX VI: RELATIONSHIP BETWEEN ESSENCE OF CARE BENCHMARKS AND THEMES GENERATED IN THE PRESENT STUDY

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## Essence of Care: Privacy and Dignity

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### Essence of Care: Self-care

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APPENDIX VII: RECOMMENDATIONS FOR IMPROVEMENTS TO THE SERVICE

Day programme
- To provide education to day patients regarding the physical consequences of eating disorders, possibly in an optional evening session format
- Individual body image work according to clients' needs
- Smaller groups for body image
- A bonding/lighter/fun/creative session to be added to the day programme and to be coordinated by the healthcare assistant
- To provide additional support for patients in the day programme in the afternoons and weekends, possibly in a graded way, so that individuals are assisted in coping during these periods in their first three months as day patients
- To provide additional support after lunch e.g. extending the programme by 15 minutes to ensure that patients have the opportunity to talk with staff about issues raised by having lunch

Outpatient Services
- To meet the needs of mothers with eating disorders and future mothers through the provision of an educational group for this client group
- Larger groups for the transition group with participants with different diagnoses
- Flexible working hours: evening sessions
- To make the assessment process more supportive
Dear Suzy,

I am very happy to confirm that you gave the service feedback on your SRFP. I remember that you prepared two reports, one for the university, and one for the service. The report was available for all to read and you discussed it with the team.

Best Wishes

Consultant Clinical Psychologist (Seconded)
QUALITATIVE RESEARCH PROJECT

ABSTRACT

Little Angels or Tiny Tearaways?

The Role of Psychologists in Reality TV.

MAY 2006

YEAR 2
ABSTRACT

With the increasing involvement of psychologists in a host of 'reality TV' programmes that have pervaded our culture in recent years ethical dilemmas and other issues have been highlighted by qualified clinical psychologists. However, less is known about the opinions of trainee clinical psychologists who are developing as professionals within this climate. Six trainee clinical psychologists participated in a focus group to explore their perspectives. Interpretative phenomenological analysis (IPA) was used to analyse the data. Five main themes emerged, these were: public views; credibility; accessibility; professional identity and ethics/responsibility. The emerging themes reflected some of the concerns of qualified practitioners which have implications for individual practice and for the profession as a whole.
MAJOR RESEARCH PROJECT

Adversarial Growth in Young People Experiencing Family Illness.

JULY 2007
YEAR 3
This study aimed to explore positive psychological growth following the challenging life circumstances faced by young people with a family member with a chronic illness or disability. Ten participants were interviewed and their transcripts analysed using social constructionist grounded theory. The higher-order categories constructed from the data were: family illness experiences, other life crises, factors promoting growth, growth, challenges and identity. The findings suggest that the participants experienced growth in relation to enhanced personal qualities such as inner strength, improved relationships, changes in religious and spiritual beliefs and a positive impact on the future. A number of influences were deemed necessary to support this growth, including social support and the negative consequences of family illness experiences. Furthermore, issues pertaining to growth had a significant impact on identity development for the young people in the study. Findings are discussed in relation to implications for services for 'young carers' and future research into identity with young people experiencing family illness or disability.
1. INTRODUCTION

1.1. THE IMPACT OF LIVING WITH FAMILY ILLNESS

1.1.1 Young Carers

In 2000 the estimated number of children in the United Kingdom living with a family member affected by chronic physical or mental health difficulties or disability was three million (Bibby & Becker, 2000). This figure contrasts with the 2001 Census in which it was estimated that there were 175,000 young carers in the United Kingdom. Much of this discrepancy can be explained by the disparity in existing definitions in the term 'young carer'. Early definitions were based on the level of care provided by the young person to their family member. For example, Walker (1996, p.3) defined 'young carer' as "a child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person which would usually be taken by an adult". However, more recent definitions have included criteria that caring has a negative impact (Aldridge & Becker, 1999) or in some way restricts a young person's life (Carers National Association, 1998). Subsequent arguments for broadening out the definitions to be more inclusive have distinguished between caring 'for' or 'about' a relative (Astil, 1998) and emphasised the significance of being affected rather than restricted by a relative's illness. However so many variations make it difficult ascertain to whom the wealth of literature (Newman, 2002) on the impact of being a 'young carer' is applicable. Furthermore, the prevalence rates are undoubtedly distorted by this lack of clarity. The emphasis of the current study is on the impact of living with a family member with a chronic illness or disability. It is possible that many or all of the participants fall into one of the many definitions of the term 'young carer', but this phrase has not been utilised due to the connotations associated with the varying definitions and discourses, which will be explored later.

1.1.2 Impact of Caring for a Relative

Thus far, the majority of research looking at the impact of family illness or disability on children and young people has focussed on identifying negative
outcomes (Newman, 2002). Some researchers suggest that the effects of family illness on children's psychological well-being and development are no less than devastating (Patenaude, 2000). Aldridge and Becker (1999) refer to such research as medical research (in contrast with social policy research) and the findings of these studies will be summarised here.

Aldridge and Becker (1993ab) draw attention to the difficulties encountered by young people experiencing family illness at school, including non-attendance, poor academic performance and bullying. The Princess Royal Trust for Carers (1999) observed that 71% of 'young carers' reported that they had been bullied at school, compared to between 10-20% of the general population of school-aged children (Smith et al., 1999). Moreover, in 1998, Dearden and Becker carried out a survey of school-aged children and found that more than a third of all 11-15 years olds reported that they had missed some school or experienced educational difficulties as a result of caring for a family member. It has been suggested that schools inadvertently collude with non-attendance, as if teachers are aware of a 'young carer's' home situation they are less likely to report truancy, due to a well meaning belief that court involvement or punishment will create more problems for the family (Bibby & Becker, 2000). However despite their benevolent intentions, ultimately all young people should be attending school to have their educational needs met and through this collusion non-attendance cannot be challenged. Furthermore, Aldridge and Becker (1993ab) highlight that at school-leaving age 'young carers' face reduced opportunities for employed work. Dearden and Becker (1998) elaborate, suggesting that as education (including factors such as attendance and high academic performance) is the path into employment and out of poverty, 'young carers' face long-term negative implications in their occupational and financial lives as a consequence of their experience of caring for their family member.

It is not only education that is affected when young people live with a relative with a chronic illness or disability. Research suggests that 'young carers' have significantly higher rates of anxiety and depression than their peers (Gardner & Preator, 1996; Grant & Compas, 1995). Furthermore, Hough et al. (2003) found that the severity of the relative's illness was associated with both internalising and externalising symptoms. However, in response to claims that 'young carers' are likely to exhibit more behavioural problems than other adolescents, Christ et al.
(1994) found that "acting out" was only likely to occur after the relative became ill if behavioural difficulties already existed prior to illness onset. 'Young carer's' self-esteem is also thought to be significantly lower than their peers (Armsden & Lewis, 1994). In fact, Siegel et al. (2000) found that children who had a parent with a diagnosis of cancer scored 40% lower on a self-esteem measure compared with normative samples. Furthermore, within the group of people termed 'young carers', empirical evidence suggests that adolescents are at greater risk of damage to their psychological well-being than young children (Armistead et al., 1995; Worsham et al., 1997).

Despite the wealth of studies into both short-term and long-term negative outcomes of living with parental illness, academics and researchers from a social policy perspective have recently begun to critique this body of research (Banks et al., 2001; Newman, 2002). Olsen (1996) and Keith and Morris (1996) have criticised the lack of robust research, citing small sample sizes, an unspecified sample population (due to the lack of consensus in definition of 'young carer') and a failure to consider confounding variables, as flaws in the argument that negative outcomes are inevitable. In particular, they state that factors such as poverty that are associated with parental disability as a result of inadequate support for the parent labelled 'disabled' have been ignored in the research, but are likely to have as significant impact on children as any caring tasks undertaken. Moreover, Hirsch et al. (1985) and Hall (1996) suggest that the absence of poverty and marital discord significantly moderate the effect of parental illness on children. Furthermore, many of the studies investigating the long-term impact of family illness on young people are conducted with clinical populations and often rely on retrospective accounts (Newman, 2002). Newman (2002) proposes that research findings describing negative outcomes have been exaggerated for use as a political tool in commissioning services for 'young carers'. As a result "children's capacity to resist and recover from adversities may have been weakened by a disproportionate emphasis on their vulnerability and the inevitability of harm" (Newman, 2002, p.620). The long-term effects of perpetuating this negative view may function to pathologise both parents and children, resulting in a self-fulfilling prophecy (Newman, 2002).
1.1.3 Politicised Arguments: Social Model of Disability versus Medical Model

As already alluded to, the 'young carers' movement has triggered much debate and controversy over recent years, with two opposing camps: the young carers research paradigm and the social model of disability perspective (Banks et al., 2001).

Banks et al. (2001) state that the social model of disability, whilst focusing on the individual with a disability, also provides an alternative perspective for considering the position of young people living specifically with parental illness. The social model of disability (Oliver, 1990) distinguishes between impairment and disability. From a social model perspective people's impairments do not cause disability, rather economic, attitudinal and social barriers within our society serve to disable people with impairments (Oliver & Barnes, 1998). Therefore parents affected by illness or impairment often experience disablement as a result of the social structuring of disability, particularly with reduced opportunities for employment or low earnings and the resultant need to be dependent on state benefit (Banks et al., 2001). From this perspective, Morris (1993) views social care as a system that reinforces dependence and instead proposes that energies should be directed into projects to promote independent living as a way of both enhancing life opportunities for the parent who is ill or disabled, whilst removing the responsibility for caring from family members. In this way, the situation of 'young caring' is viewed as a consequence of the inequality experienced by disabled people (Morris, 1993) and hence services should be geared towards meeting the needs of the disabled person themselves.

This assertion has proved contentious with the young carers movement, as there appears to be an impasse between, on the one hand placing the rights and support needs of children at the top of the agenda (Aldridge & Becker, 1993a), whilst on the other promoting the rights of people with a disability and providing services to them directly, which in turn is thought to be a way to support children who provide care. The young carers movement, who promote the first argument, have been criticised, as by creating services for 'young carers', they run the risk of leaving the parent unsupported and 'blamed' for their inadequacy in fulfilling parental duties (Newman, 2002). Furthermore many of such young carers projects have not been thoroughly evaluated to determine their efficacy (Newman, 2002) and instead rely on the 'do no
harm principle'. Meanwhile, the social model of disability perspective has been condemned for proposing a scheme whereby it is felt that 'young carers' will be made invisible and hence neglected as no service can ensure that all caring responsibilities will be removed from family members (Aldridge & Becker, 1993a). Furthermore it has been highlighted that other aspects of living with a relative who is ill, discounting caring responsibilities, mean that young people require support they would not get without young carers projects.

Despite a recognition by most working with 'young carers' that ultimately an approach that considered the needs of the whole family, not just the relative experiencing illness or disability or the young person, would be most beneficial, Newman (2002) suggests that 'selling' the notion of supporting relatives to professionals, government and media is somewhat more difficult than supporting 'young carers'. Newman (2002, p.620) goes on to state "a pre-occupation with the rights of children has diverted attention, and possibly resources, from the needs of families".

1.1.4 Pathological Views

The negative focus of literature regarding the impact of living with a relative with an illness or disability has historical roots in the psychological notion of 'parentification'. Parentification has been defined as the expectation that one or more children will fill the parental role in the family system (Boszormenyi-Nagy & Spark, 1973). This concept emerged from attachment and systemic theories, and the professional literature understandably emphasises the pathological aspects of parentification (Barnett & Parker, 1998), implicating severe deleterious effects for the child. A proportion of young people living with a relative who is chronically ill or disabled could be described as 'parentified' (Aldridge & Becker, 1993b), as particularly if the relative is a parent, the young person may be required to take on parental roles towards several family members, such as responsibility for looking after siblings, providing the parent with emotional and practical support and completing household chores (Byng-Hall, 2002).
Jurkovic (1997) distinguished between adaptive and destructive parentification. Whilst adaptive parentification is considered to be a transient experience in which the child's identity does not become enmeshed with the parental role; destructive parentification is thought to include developmentally inappropriate and excessive responsibilities and emotional care-taking (Byng-Hall, 2002). Bowlby (1977, p.207) related the experience of destructive parentification to compulsive care-giving in later life, whereby the individual who cared for their parent goes on to form relationships in which they are "always in the role of giving care, never that of receiving it". In fact, Frank et al. (1999) reported that fifty percent of past carers attributed their chosen career in caring professions to care-giving experiences earlier in their lives. However, when it comes to whether an experience was destructive or adaptive it is complex to assess what might be developmentally inappropriate across cultures or even within a culture of origin, and as already discussed, often parents do not receive support themselves in order to minimise the responsibilities children undertake.

There has been a relatively recent acknowledgement that parentification may not always represent a sign of childhood deprivation, but instead can be seen as an opportunity for developing early competence (Barnett & Parker, 1998). Byng-Hall (2002) draws attention to the utility of learning about caring roles early on as preparation for later life experiences. Furthermore, successful coping attempts in the context of parentification are likely to provide the foundations for building upon self-efficacy and self-esteem and hence lead to an improved perceived ability to cope with challenges and plan for the future (Barnett & Parker, 1998). Moreover Barnett and Parker (1998) elaborate that even experiencing the negative effects of parentification does not prevent the possibility of extraordinary accomplishments as an adult.

1.1.5 Family Ecology Framework

Pederson and Revenson (2005) described their development of a family ecology model, designed to explicate the links between parental (rather than family) illness, family functioning and adolescent well-being. Drawing on empirical research, family systems theory (Kazak, 1989) and human ecology (Bronfenbrenner, 1977), the
model sought to explore not only the relationship between parental illness characteristics and outcomes (for families and adolescents), but also the variables mediating this relationship, including role redistribution, youth stress and threat to the family.

Their literature review revealed much of the evidence already discussed regarding the negative effects of parental illness on adolescents' well-being, in the form of an increased risk of depression, anxiety, and low self-esteem (Pederson & Revenson, 2005). However, they were able to identify only four studies recognising positive well-being as a potential outcome for children coping with parental illness. Furthermore, these studies examined characteristics such as self-esteem (which could have been negatively impacted by the illness) rather than examining any positive personal growth. Pederson and Revenson (2005) stated that they were unable to find any literature that examined any positive outcomes among adolescents of parental illness and that such research is necessary and should aim to identify factors that enhance growth outcomes. This under-researched area is important, as the recent developments in positive psychology suggest that an alternative clinical intervention to the alleviation of distress is the facilitation of growth (Linley & Joseph, 2004).

1.1.6 Positive Psychology

It is undoubtedly necessary to draw the possible risks to a child's well-being to the awareness of professionals. Increased awareness can aid clinicians to be vigilant to possible difficulties, plan interventions and help young people to access support. However, Newman (2002) suggests that that the disproportionate emphasis on risk minimises the acknowledgement of young people's capacity to resist and recover from adversity, hence obscuring the strengths and resilience they possess. Furthermore, simplifying responses to adversity to only those necessary for making a diagnosis can mask other possible positive changes that also have clinical relevance (Brett, 1996). Perhaps, as Wolin et al. (1995, p.24) suggest, "we need a list of strengths as powerful and as validating as the florid vocabulary of diseases found in the DSM-IV to combat our national obsession with pathology".
Although so-called 'positive psychology' (Carr, 2004; Seligman & Csikszentmihalyi, 2000) is often considered a new direction, Tedeschi and Calhoun (2004) remind us that Maslow was arguing for more research to consider psychological well-being in people who are “healthy” in 1970. This shift in emphasis towards assessing and acknowledging the strengths and resources of individuals can lead to alternative ways of supporting people through challenging life circumstances, by drawing on and facilitating positive adaptation. Richardson (2002, p.307) feels this represents a “paradigm shift from a reductionistic, problem-oriented approach to ‘nurturing strengths’ as a prevalent theme across academic disciplines”. This context has provided the foundations for the large body of research that now exists into resilience in ‘high-risk’ children (Selekman, 1997). However, Pederson and Revenson (2005) point out that despite the identification of resilience and strengths, there is still limited research into how individuals actively utilise challenging circumstances as a transformational experience for positive growth outcomes.

1.2. ADVERSARIAL GROWTH

1.2.1 The Concept of Adversarial Growth

Definition

In recent years there has been an emergence of research looking at how people transform the experience of major life challenges into positive personal growth (Zoellner & Maercker, 2006). Many terms have been used to describe this phenomenon, including posttraumatic growth (Tedeschi & Calhoun, 1995; 2004), adversarial growth (Linley & Joseph, 2004), stress-related growth (Park & Fenster, 2004), thriving (O’Leary & Ickovics, 1995) and benefit-finding (Calhoun & Tedeschi, 1991). For the purposes of this study, the term adversarial growth will be adopted, as living with family illness may not fit traditional definitions of a ‘traumatic event’, but is more likely to incorporate the experience of struggling with difficult life circumstances.

Adversarial growth refers to a “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi &
Calhoun, 2004, p.1). Although the phenomenon of adversarial growth has only come to the forefront of the research arena in psychology in the past decade, the notion that suffering and distress can be a source of positive transformation dates back thousands of years in both religious and philosophical writings (Tedeschi & Calhoun, 1995). Calhoun and Tedeschi (1999) emphasise that growth is not a consequence of the event (e.g. family illness) itself, but instead is produced by the person's struggle to come to terms with what has happened. Furthermore, adversarial growth is thought to have a transformational quality, whereby the individual does not simply return to pre-crisis levels, but instead has developed beyond their previous level of adaptation or psychological functioning in some domain (Zoellner & Maercker, 2006). Research suggests that between 30% and 90% of people facing some form of crisis will experience a degree of growth (Tedeschi & Calhoun, 1995). However, that is not to say that individuals who experience adversarial growth do not experience negative consequences as a result of their stressful situation (Tedeschi & Calhoun, 2004). Theorists in the field of adversarial growth are keen to draw attention to the notion that growth and distress are not opposite ends of the same continuum (Linley & Joseph, 2004) and therefore, interventions to alleviate distress will not automatically promote growth and vice versa (Frazier et al., 2001). Therefore if a young person who has a relative who is ill experiences the negative consequences described in the research cited earlier, this does not inevitably mean that they will not have gained any positive growth as a consequence of coming to terms with family illness. Furthermore, it is vital that these negative outcomes are not dismissed in order to focus on growth, as both distress and growth are important considerations, particularly in planning interventions (Calhoun & Tedeschi, 1999).

**Differentiation with Other Concepts**

Tedeschi and Calhoun (2004) draw attention to the distinction between adversarial growth and related concepts, such as resilience and hardiness. They highlight that resilience, which has been defined as "the ability to withstand and rebound from disruptive life challenges" (Walsh, 2008, p.899) and hardiness, which has been conceptualised as present in "individuals who remain healthy after dealing with high degrees of life stress" (Lambert & Lambert, 1999, p.11) have both
frequently been studied in young people who experience very difficult life circumstances, but return to pre-crisis levels of functioning. However, adversarial growth refers to a change that goes beyond the capacity to resist or cope with highly stressful circumstances and find benefit from them in a transformational fashion (Tedeschi & Calhoun, 2004). Pat-Horenczyk and Brom (2007, p. 380) expand upon this distinction by referring to resilient or hardy individuals as “bouncing back” from adversity, while individuals who go on to experience growth “bounce forward”.

**Domains**

A number of different domains of adversarial growth have been identified, in particular Tedeschi and Calhoun (1996) specify a five-factor approach in their development of a measure of posttraumatic growth: (1) a greater sense of personal strength, which can also seemingly paradoxically occur with a greater sense of vulnerability; (2) emergence of new possibilities in life, developing new interests, activities and even life paths; (3) a change in relationships with family and friends, such as a greater sense of intimacy, warmth and emotional expression; (4) a heightened appreciation of life and altered sense of priorities; and (5) a change in spiritual and religious beliefs and practices.

**Research**

Linley and Joseph (2004) cite a number of studies demonstrating the occurrence of adversarial growth in people whose challenging life circumstances ranged from bereavement to acute and chronic illness, from assaults to natural disasters. The concept of adversarial growth appears to be pertinent to a wide range of people experiencing a wide range of challenges (Tedeschi & Calhoun, 2004). In their review, Linley and Joseph (2004) clarified a number of the findings around the concept of adversarial growth. For example, they found that the higher the perceived threat of harm, the higher the levels of reported growth would be. Satisfaction with perceived social support rather than the quantity or quality of social support was associated with higher levels of adversarial growth, and women were more likely to report
growth than men. Linley and Joseph (2004) also stated that quality of life was not related to reported adversarial growth.

A number of measures have been developed to tap into the different dimensions or domains of adversarial growth (Hiskey et al., 2006). Possibly the most frequently cited is the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996), which employs 21 items to measure the five dimensions of growth described above. Despite being utilised to further explore the concept and develop the evidence base in this field, it is as yet unclear as to whether the factors employed in the Posttraumatic Growth Inventory are cross-culturally valid or even appropriate to experiences of different trauma survivors (McMillen, 2004). Moreover, as growth appears to have both qualitative and quantitative differences in crisis survivors, it would seem that both methodologies are potentially suitable for considering different aspects of the experience of adversarial growth (Tedeschi & Calhoun, 2004). Tedeschi and Calhoun (1995) suggest that the use of qualitative analysis of extensive interviews with people who have experienced adversity is a key step in furthering understanding, particularly with under-researched populations.

Clinical Use

Understandably, thus far the majority of clinical or therapeutic work has focussed on how individuals are negatively impacted by adversity (Calhoun & Tedeschi, 1999). However, with the renewed energies into developments in the field of positive psychology, this is beginning to shift. Linley and Joseph (2004) state that the facilitation of adversarial growth is a valid therapeutic aim. This seems to fit with Herman's (1992, p.133) assertion that "the first principle of recovery is the empowerment of the survivor". However, as has already been discussed, growth and distress are not opposite ends of a continuum. Therefore the facilitation of adversarial growth as a clinical intervention would represent a different type of intervention to the alleviation of distress, and hence it is important to consider both of these outcomes comprehensively. In their book 'Facilitating Posttraumatic Growth' (1999), Calhoun and Tedeschi offer guidance for clinicians wanting to assist their clients to foster adversarial growth.
1.2.2 Tedeschi and Calhoun's (1995; 2004) Model of Posttraumatic Growth

Tedeschi and Calhoun (1995; 2004; Calhoun & Tedeschi, 2006) have developed possibly the most comprehensive model of adversarial growth currently available. They draw on Janoff-Bulman’s (1992) theory of trauma impact, which proposes that individuals possess a general set of beliefs and assumptions about the world which they rely on to make sense of what happens to them and guide their actions. Traumatic events or life challenges can shake the very core of these ‘assumptive worlds’ (Kuhn, 1970), leading to significant distress and the need to rebuild one’s view of the world after the crisis.

Calhoun and Tedeschi (2006) emphasise a number of pre-requisites before growth can take place. Firstly, individual personal qualities may increase the likelihood of experiencing adversarial growth. People scoring highly on extraversion and openness to experience personality variables have been found to be more likely to report adversarial growth (Tedeschi & Calhoun, 1996). They also acknowledge that an individual needs to engage in initial coping responses to manage the distress provoked by the event and disruption to their assumptive world or schema. Furthermore, this disruption may require a person to relinquish certain goals or assumptions that have been invalidated by a crisis.

Within their model, Tedeschi and Calhoun (2004) emphasise the importance of cognitive activity in terms of rebuilding assumptive worlds. They propose that rumination, or cognitive engagement with the content of the crisis is necessary to establish a sense of comprehensibility about the event. Although rumination generally has negative connotations, Nolen-Hoeksema and Davis (2004) distinguish between brooding and reflective rumination, suggesting that the latter forms the cornerstone of “repair, restructuring and rebuilding” of a person’s schemas (Calhoun & Tedeschi, 2006, p.10). Hence schemas reconstructed through engagement in ruminative processes include increased awareness of personal resources and better sense of coping abilities. It has been proposed that revision of schemas that produce comprehensibility may be an intermediate step to adversarial growth (Calhoun & Tedeschi, 2006). Research supports this component of the model, as evidence suggests that the frequency of cognitive activity engaged in is correlated with the levels of adversarial growth reported (Linley & Joseph, 2004).
At the same time as an individual is engaging in cognitive activity, Calhoun and Tedeschi (2006) also propose the person is being influenced by proximal and distal cultural elements. Calhoun and Tedeschi (2006) describe distal cultural elements as the broad societal and cultural context (for example a country). Such influences shape how an individual understands what has happened to them. For example, the dominant script of "a stiff upper lip" in British culture may influence how a person manages adversity. Proximate culture relates more to a person's social networks, or 'primary reference groups', which include the people who have immediate influence over an individual. Three elements to the primary reference group are thought to be important in growth, namely: the responses afforded when a person discloses the event; the congruence between the individual's interpretation of the event and that of the primary reference group; and whether adversarial growth is or has been modelled within the primary reference group (Calhoun & Tedeschi, 2006).

Finally, Calhoun and Tedeschi (2006) acknowledge that adversarial growth has close links to both the development of wisdom about life and also the modification and further development of life narratives.

1.2.3 Narrative Model

Within their model, Calhoun and Tedeschi (2006) acknowledge that personal narratives are an important component of adversarial growth, as a traumatic event forces an individual to reconstruct their narrative in order to make meaning from their experience. However, Neimeyer (2004; 2006) further elaborates this conceptualisation of adversarial growth as a form of "meaning-making" following adverse life circumstances. Within this framework, Neimeyer (2005) contributes to the understanding of the differentiation between resilience and adversarial growth by proposing that resilient individuals assimilate the crisis into their narrative, whilst individuals who go on to experience growth have to reconstruct narratives that have been disorganised or disrupted to accommodate the experience.

Within a narrative model, an individual's sense of self is established through the stories they tell or that are told about them (Neimeyer, 2004) and it is this self-narrative that Neimeyer (2004; 2006) proposes is shaken by life crises. Furthermore,
narration is thought to serve inter- and intra-personal functions. People gain social validation through the recounting of adverse experiences, leading to social support, which is thought to enable healing and growth (Neimeyer, 2006). Finally, narrative processes are thought to occur at a broadly social level in which a context can be developed to support adversarial growth (Neimeyer, 2004). For example, it is possible that within the context of a 'young carers' group ways of talking about and making sense of experiences might facilitate adversarial growth. Moreover, as social groups have their own cultural beliefs and assumptions, it is worth considering the possibility that adversarial growth might represent adherence to a particular cultural script, that is, a story passed down through the generations that good things come from traumatic events (Linley & Joseph, 2004).

1.2.4 Adversarial Growth and Adolescence

Despite acknowledgement that adversarial growth is likely to be applicable to adolescents (see Tedeschi & Calhoun, 2004), very limited research exists assessing the construct in this population (Kilmer, 2006; Milam et al., 2004). Albeit the existence of seven instruments thought to measure dimensions of adversarial growth (Linley & Joseph, 2004), not one is designed for the assessment of adolescents.

The first study that examined adversarial growth in adolescents concluded that not only does growth occur, but furthermore it is linked with lower levels of substance abuse (Milam et al., 2004). This research used a modified version of the Posttraumatic Growth Inventory, designed for use with adults and found that the older the adolescent was, the higher the level of reported growth. This finding is consistent with the proposition that a certain level of cognitive maturity is required to find meaning or identify salient benefits as a result of adversity (Linley & Joseph, 2004). Within the context of Tedeschi and Calhoun's (2004) theory, this seems logical, as if schemas have to be shattered by an event to provide the necessity for rebuilding assumptive worlds, it follows that schemas must have been sufficiently developed in order to be shattered. Furthermore, Calhoun and Tedeschi (1999) suggest that by late adolescence, identity has been formed and that identity provides a basis for an individual to integrate any traumatic event into their sense of who they
are. Calhoun and Tedeschi (1999) use this premise to explain why trauma early in childhood may have more severe, negative longer-term implications, as the trauma can disrupt identity formation.

1.2.5 Adversarial Growth and Caring

Over recent years there has been increased interest in the effects of trauma on an individual’s family or close social supports. Throughout the last five years in particular, evidence has begun to emerge to suggest that partners and offspring experience adversarial growth as an outcome of a relative’s illness. For example, Pakenham (2005) investigated benefit-finding in people caring for a spouse or other relative with multiple sclerosis. He found that carers reported a wide range of benefits, including changed priorities, greater insights into hardship, strengthened relationships, personal growth and greater appreciation of life. Furthermore he looked at the associations between perceived growth reported by care recipients and caregivers and found correlations across all domains of reported growth. Finally, Pakenham (2005) also concluded that benefit-finding emerges later in the adjustment process, as for his participants, growth increased with the duration of caring and illness. This is not an isolated finding. The wives of men with prostate cancer have also reported changes consistent with adversarial growth (Thornton & Perez, 2006), whilst the partners of women recovering from breast cancer indicated that since their partner’s illness they had developed more personal strength and begun to recognise new possibilities for life (Manne et al., 2004).

Two perspectives on this process of growth related to family illness seem to emerge. One considers that the challenges associated with the illness can impact relatives who do not experience the illness themselves (i.e. vicarious trauma), while the other perspective focuses on “caring” as a source of chronic stress for a relative. In reality these two positions seem impossible to distinguish, although it is noteworthy that in a recent study of the adult daughters of breast cancer survivors, those daughters who provided care for their mothers reported more adversarial growth than those who did not (Mosher et al., 2006). Therefore it is possible that caregiving makes it more likely for a relative to experience adversarial growth.
Although anecdotal evidence from interviews (e.g. Aldridge & Becker, 1998ab; Dale & Altschuler, 1999) conducted with 'young carers' points at the development of growth areas such as maturity and empathy in the context of their caring role, research has not specifically explored these positive changes and the sense made of them by the young people themselves. However, when parents were asked about the benefits their children received from caring for a relative, responses included increased understanding of disability, development of practical skills, improved family relationships and increased maturity and independence (Banks et al., 2001). Furthermore, Banks et al. (2001) stated that in a school survey a third of young people who helped look after a relative reported that it made them happy. Given the preliminary evidence that adversarial growth is possible in both adolescents and in people living with a relative with a chronic illness, exploring the concept with people termed 'young carers' seems a coherent and potentially fruitful line of enquiry.

1.2.6 Critique of Adversarial Growth

It is important to be mindful of the helpful critiques that exist in relation to the construct of adversarial growth (e.g. McMillen, 2004; Park, 2004; Wortman, 2004). For example, McMillen (2004) highlights that only limited consideration is given to the broader cultural context in existing theories. Distal cultural influences have the potential to shape growth experiences and cognitive processes, but have not been given as much prominence as McMillen (2004) believes necessary. An example relates to the dominant Western narrative "what doesn't kill us makes us stronger". This cultural narrative has the potential to influence the way an individual makes sense of their experience and hence rebuilds their schemas. However, the role of non-Western cultural narratives in determining responses to adversity is under-explored, as is the construction of what constitutes a growth experience in non-Western cultures (Pals & McAdams, 2004).

Another criticism often directed at researchers investigating adversarial growth is that self-reported growth may actually represent a defensive illusion or coping mechanism (Wortman, 2004; Zoellner & Maercker, 2006). Zoellner and Maercker (2006) situate this hypothesis in the context of Western culture's need to believe
that significant life events are controllable, comprehensible and non-random, which in turn leads to survivors needing or wanting to convince themselves that something good has come out of adversity. Wortman (2004) suggests that in order to test this hypothesis, it is necessary to conduct prospective studies and gain objective reports of growth from significant others.

Finally, it has also been suggested that there has been a lack of consideration paid to negative changes that occur when a stressful life events takes place (Wortman, 2004). Wortman (2004) suggests that the number of negative effects experienced by an individual who also reports one dimension of growth must surely outweigh the small element of reported growth. However, Tedeschi and Calhoun (2004) have repeatedly expressed their view that negative effects, such as distress, and positive effects, such as growth are not inversely related and can occur alongside each other. Hence to measure and explore growth within an intervention in no way precludes measuring and addressing the enduring adverse effects of an individual's experience. Moreover, in the current study, an abundance of information on the adverse effects of living with a relative with a health difficulty or disability already exists, and young people will be asked about changes in their lives rather than specifically about growth to allow the full range of their experiences to be explored.

1.3. THE CURRENT STUDY

Two separate lines of preliminary evidence are beginning to suggest that adversarial growth is a phenomenon that might be applicable to relatives who have a family member with a chronic illness and also to adolescents. However limited research exists into young people's experiences of adversarial growth and as Tedeschi and Calhoun (1995) suggest that qualitative research should be the first step in exploring the existence of a phenomenon in under-researched populations, qualitative research with young people would seem to be a necessary first step to explore the concept's relevance, meaning and construction with this population. Furthermore, although anecdotal evidence from interviews (e.g. Aldridge & Becker, 1993a) conducted with young people providing care for family members points at the development of growth areas such as maturity and empathy in the context of
their caring role, research has not specifically explored these positive changes and the sense made of them by young people themselves. Pederson and Revenson (2005) state that such research is vital in order to identify factors that promote growth and positive well-being in young people living with family illness.

The present study seeks to build on the literature regarding the impact of family illness or disability on young people from a resilience-based perspective. It aims to explore the experiences of adversarial growth in 16-19 year olds who have a parent or sibling with a chronic illness or disability; to learn if this concept is applicable to the young people participating in the study and how they believe it has developed. In this way, the current study will also expand on the limited research-base exploring adversarial growth in young people. It is hoped that the results of this study may contribute to emerging literature regarding how services can employ alternative clinical approaches to the alleviation of distress through recognising strengths and facilitating growth.
2. METHOD

2.1. QUALITATIVE METHODOLOGY

2.1.1 Overview of Qualitative Methodology

Qualitative research has been defined as a broad range of methods "designed to describe and interpret the experiences of research participants in a context-specific setting" (Ponterotto, 2005, p. 128). Such methods privilege the exploration of meaning and understanding from the perspective of the participants (Willig, 2001). Unlike quantitative approaches, which stress the positivist paradigm's tenets of replicability, generalisability, uniformity and objectivity (Ponterotto, 2005), qualitative approaches offer the opportunity to freely explore the complexities of numerous interpretations and meanings of thoughts, feelings and actions within their local context (Henwood & Pidgeon, 1995).

Qualitative research encompasses a number of methodologies, each with differing underpinning assumptions and philosophies (Ponterotto, 2005). It is thought that researchers are drawn to a particular methodology based on their own philosophical stance and school of thought, as well as their personal experiences, beliefs and values (Charmaz, 1990).

2.1.2 Grounded Theory

Grounded theory (Glaser & Strauss, 1967) has been described as a general methodology or way of thinking about and conceptualising data (Henwood & Pidgeon, 1995). The grounded theory approach is an emergent methodology and therefore suitable for the generation of a theory 'grounded' or embedded in the data (Henwood & Pidgeon, 2003). A grounded theory is generated through an iterative process involving the simultaneous collection and analysis of data (Glaser & Strauss, 1967). According to Glaser and Strauss's original description (1967) the core components of grounded theory methodology also include conducting the literature review subsequent to the analysis to ensure that codes are constructed from data rather than prior knowledge of theory and sampling for theory construction rather
than representativeness (Charmaz, 2006). Constant comparison is another significant component within grounded theory, which refers to continually sifting and comparing elements (Pidgeon, 1996) across the duration of a study. The comparison of elements of the data, conceptual categories and theoretical assumptions allows for heightened sensitivity to the complexities of the similarities and differences within the data (Pidgeon, 1996).

The original formulation of grounded theory, however, encompassed an epistemological quandary, labelled by Hammersley (1989) as "the dilemma of qualitative method". Such a dilemma arose from the juxtapositioning of grounded theory's philosophical roots in "induction" of a theory from the data, with the interpretative process of generating new understandings (Henwood & Pidgeon, 2003). Such debate has been influential in the constructivist revision of grounded theory (Charmaz, 1995; 2006). This constructivist revision also allows the researcher to reflect upon their own creative and interpretative role in the analyses, acknowledging that the resulting theory will be a construction of the research process (Charmaz, 1995; 2006). Furthermore it allows for acknowledgement that this process often begins with a literature review prior to analysis, due to the pragmatic requirements of many research projects (Charmaz, 2006). Hence subjectivity and reflexivity are explicitly integrated into the approach. Furthermore in a social constructionist approach to grounded theory the data from the lived experiences of the participants is seen as a basis to explore how participants are constructing their experiences and worlds (Charmaz, 2006). Hence, any grounded theory constructed from a research project represents a context-specific interpretive portrayal of the studied world within a particular time period rather than a singular theoretical certainty or truth.

2.1.3 Rationale for Using Grounded Theory

The epistemological stance of Charmaz’s (2006) version of grounded theory was adopted by the current study for a number of reasons. According to Henwood and Pidgeon (2003), grounded theory is a particularly suitable methodology for studies investigating phenomena (e.g. adversarial growth) within their local context (e.g.
young people living with family illness). Therefore grounded theory seems to be suitable for addressing the research question of the current study. Grounded theory is also deemed particularly appropriate when existing theory is incomplete, inappropriate or absent (Henwood & Pidgeon, 1992). As has already been discussed research into young people's experiences of adversarial growth is limited, while research into young people living with family illness' experiences of adversarial growth is absent. Furthermore, Pederson and Revenson (2005) state that not only do we need to explore young people's experiences of adversarial growth, but we also need to try and understand how it comes about. In this context, grounded theory seems to be a fitting approach for the current study. Finally, a social constructionist approach to grounded theory seemed to resonate with the researcher's personal position regarding philosophy of science, which will be discussed further in the reflexivity section (Ponterotto, 2005).

2.2. PARTICIPANTS

2.2.1 Recruitment

Participants were recruited from Young Carers' Services and sixth form colleges throughout the South East of England. Twenty Young Carers' Services were contacted to enquire if they had any young people who met the inclusion criteria (see below) and might be willing to participate in an interview. Of these services five agreed to send out information packs consisting of a letter, information sheet and consent form to young people they thought might be interested. Estimates from the services suggest that approximately 70 packs were sent out in total, indicating a response rate of around 5%. The information sheet provided details regarding the purpose and procedure of the study and gave the researcher's contact details. Participants proceeded to contact the researcher directly via post or e-mail and a convenient time was arranged for the interview. Advertisements for the study were also placed in the news bulletins of two sixth form colleges and again, participants were invited to contact the researcher directly if they were interested in participating in the study.
2.2.2 Demographics

Ten participants took part in the study, three males and seven females. The participants ranged in age from 16-19 years. Participants lived with parents or siblings with chronic illnesses or disabilities. The duration of relatives’ illnesses ranged from four to 45 years, hence some participants had been born into families with existing disability or illness, whilst for others family illness or disability had developed in their childhood or adolescence. The table below shows the demographic data collected for each participant.

Table 1: Participant's Demographic Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Relative</th>
<th>Illness/Disability</th>
<th>Age when became ill</th>
<th>Recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sally</td>
<td>F</td>
<td>17</td>
<td>White British</td>
<td>Father</td>
<td>Alcoholism</td>
<td>Birth</td>
<td>Young Carers Group</td>
</tr>
<tr>
<td>2. Kwame</td>
<td>M</td>
<td>19</td>
<td>Black British African</td>
<td>Mother</td>
<td>Stroke</td>
<td>14</td>
<td>Young Carers Group</td>
</tr>
<tr>
<td>3. Jenny</td>
<td>F</td>
<td>16</td>
<td>White British</td>
<td>Brother</td>
<td>Autism</td>
<td>8</td>
<td>Young Carers Group</td>
</tr>
<tr>
<td>4. Nina</td>
<td>F</td>
<td>17</td>
<td>British Asian Pakistani</td>
<td>Brother</td>
<td>Developmental delay</td>
<td>7</td>
<td>Young Carers Group</td>
</tr>
<tr>
<td>5. Gemma</td>
<td>F</td>
<td>16</td>
<td>White British</td>
<td>Step-brother</td>
<td>Down’s syndrome</td>
<td>12</td>
<td>College</td>
</tr>
<tr>
<td>6. Anthony</td>
<td>M</td>
<td>17</td>
<td>White British</td>
<td>Mother and brother</td>
<td>Deaf and spina bifida</td>
<td>Birth</td>
<td>College</td>
</tr>
<tr>
<td>7. Angel</td>
<td>F</td>
<td>19</td>
<td>White British</td>
<td>Father</td>
<td>Cancer</td>
<td>6</td>
<td>College</td>
</tr>
<tr>
<td>8. Natalia</td>
<td>F</td>
<td>16</td>
<td>White Polish</td>
<td>Mother</td>
<td>Cancer</td>
<td>11</td>
<td>College</td>
</tr>
<tr>
<td>9. Elizabeth</td>
<td>F</td>
<td>17</td>
<td>White British</td>
<td>Brother</td>
<td>Epilepsy and autism</td>
<td>3</td>
<td>College</td>
</tr>
<tr>
<td>10. Ewan</td>
<td>M</td>
<td>17</td>
<td>White British</td>
<td>Sister</td>
<td>Rett’s syndrome</td>
<td>10</td>
<td>College</td>
</tr>
</tbody>
</table>
2.2.3 Inclusion Criteria

1. Participants with a family member with a chronic illness or disability that has lasted at least two years.

2. Participants aged between 16-19 years.

The inclusion criteria intended to ensure that participants would have experienced life with their family member's illness or disability whilst an adolescent.

2.2.4 Ethical Considerations

The study was granted ethical approval by the University of Surrey School of Human Science's Ethics Committee (see Appendix i). An outline of the main ethical issues considered in conducting the study can be found in Appendix ii.

2.3. PROCEDURE

2.3.1 Design of Interview Schedule

Intensive qualitative research interviews offer detailed, open-ended exploration of aspects of life which participants have particular experience of. Interviewing is a flexible, emergent technique, during which the interviewer can pursue ideas and issues as they transpire. For this reason, Charmaz (2006) states that individual interviews are a particularly suitable method for gathering data for a grounded theory project.

However, grounded theory interviews differ from interviews using other qualitative methodologies, as in grounded theory, as the data collection progresses the interview topics are narrowed to gather more specific information for development of the theory (Charmaz, 2006). Hence depending on the direction in which participants' accounts are taking the data, questions may be added or removed from the interview schedule. This focussing in as the analysis progresses necessitates an initial interview schedule that is broad enough to encompass the main issues and
processes of the experiences under investigation. Throughout the course of the research, questioning becomes more selective as ideas are checked out and leads followed up.

The interview schedule (see Appendix vi) was designed to incorporate questions regarding the possible impact of living with a family member with a chronic illness or disability on participant’s views of themselves and the possible impact of these experiences on their future. Questions concerning any changes relating to living with family illness were included, which offered participants an opportunity to discuss any elements of adversarial growth. Furthermore, questions were also included regarding how participants felt any changes noted (positive or negative) came about and the significance of such changes. Open-ended questions encouraged the participants to speak freely about areas they considered to be important (Smith, 2003).

2.3.2 Interviews

Interviews with members of Young Carers’ services were conducted at the young person’s home, whilst interviews with people recruited through sixth form colleges were conducted in a room at the college. The interviews lasted between thirty minutes and one hour. Although the interview schedule was followed as closely as possible the amount of prompts and order of questions varied to fit with the participant. At the end of the interview participants were given the opportunity to ask any questions and to reflect upon their subjective experience of the interview. Each interview was audio-recorded and transcribed verbatim as soon as possible following the interview in order to begin the process of analysis early on.

2.4. ANALYTICAL PROCEDURE

2.4.1 Theoretical Sampling

Theoretical sampling involves seeking out specific people, events or information in order to refine and develop ideas (Charmaz, 2006). This leads to further definition
of theoretical categories and subsequent strengthening of the emerging theory (Strauss & Corbin, 1990). In grounded theory, data collection is conducted in batches, whereby each batch consists of several interviews that are analysed before data collection can proceed onto the next batch. As the sample size in the current study was limited, theoretical sampling on the basis of defining characteristics of participants or particular experiences was not possible. However, after analysis of the first batch (four transcripts) it seemed important to further refine the ideas regarding the way a person's identity as a 'young carer' influences their perceptions of change, and hence participants from colleges who did not attend a young carers service were recruited.

Furthermore, after initial analysis of the first batch of data the interview schedule was adapted. Thus questions generating irrelevant or over-saturated responses were removed from the interview schedule, whilst questions and prompts tailored towards collecting data addressing developing ideas were inserted. As the analysis progressed questioning became more selective as ideas were checked out and leads followed up. Specifically, the final batch concentrated more on following up emerging ideas around coping strategies and participant's views of the impact of their experiences on their futures.

2.4.2 Constant Comparison

Constant comparison is a method at the heart of grounded theory that utilises inductive processes to initially compare data with data, and when theory has begun to emerge to compare data to theory (Henwood & Pidgeon, 2003). Constant comparison therefore allows full exploration of the complexities, similarities and differences of the data (Henwood & Pidgeon, 1992). Charmaz (2006, p.179) refers to this process as an interrogation of "relationships between your categories and fundamental aspects of human existence", which ultimately offer rigorous scrutiny of the construction of the theory, ensuring it is grounded in the data.

2.4.3 Coding
Grounded theory offers an explicit but flexible set of strategies for analysing qualitative data (Charmaz, 1995). The current study utilised the approach described by Charmaz (2006) as it appeared to be most in accordance with the epistemological stance and research question. The initial stage of analysis was line-by-line coding, involving naming each line of data from a transcript (Glaser, 1978). This form of initial coding was selected as it allowed the researcher to keep closer to the data for the initial stages of the analysis, seeing nuances or intricacies that might have been missed if larger sections of the data were selected for coding. Following Charmaz’s (2006) recommendations, coding for action was used, as using a language of action helps avoid producing an entirely descriptive theory and making conceptual leaps.

Following the process of line-by-line coding for three transcripts, focused coding began, in which line-by-line codes were selected that represented larger selections of data (Charmaz, 2006). Focused codes are more conceptual and directed than line-by-line codes (Glaser, 1978) and provide an intermediate level before the identification of conceptual categories. Glaser and Strauss (1967, p.87) describe a category as a “conceptual element in a theory”. Categories were identified through the processes of constant comparison and memo-writing (Charmaz, 2006). When focused codes appeared to be significant concepts used to explain views, occurrences or processes within the data such codes were raised to categories (Charmaz, 2006).

2.4.4 Memo-writing

“Memos are the theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data, and during memoing” (Glaser, 1998, p.177). Throughout the analysis, from initial stages of line-by-line coding, memos were used to explore the concepts as they were emerging in relation to other data and existing theory, thereby synthesising the conceptual links between data and theory (Charmaz, 2006). See Appendix viii for an example of a memo.

2.4.5 Saturation
Grounded theory analysis has the potential to continue indefinitely, as new perspectives on the data are always possible (Glaser & Strauss, 1967). Although saturation is often considered to be the aim of many qualitative research methods, Willig (2001) recognises that such an idea serves as a goal rather than a function. In the current study, saturation was not possible, as due to the small scale and time constraints it is likely what has been developed represents a “rich conceptual analysis of lived experience and social worlds rather than substantive or formal theory” (Charmaz, 1995, p. 48). However it is felt that the analysis represents an interpretation of the experiences of adversarial growth encountered by young people living with a family member with an illness or disability, as was the aim of the current study.

2.5. REFLEXIVITY

I self-identify as a 24-year-old, White British, female Trainee Clinical Psychologist. During my undergraduate study I was exposed to quantitative research methodologies and associated positivist assumptions and philosophies. A personal attempt to explore the qualitative paradigm was supported by a post-positivist approach to supervision whereby I was encouraged to quantify themes elicited from interview data.

During my training, I have been introduced to ideas from the systemic family of therapies, including social constructionist and narrative ideas. I have developed this interest in my clinical work with service users and their families and have found that such approaches have offered me the opportunity to consider multiple perspectives at a more in-depth level and to further understand the importance of hearing a person’s story. I considered this to be particularly useful in helping me to attempt to understand the experiences of young people who identify as living with a family member who is ill, in the context of my own identification as a 24-year-old who did not experience chronic family illness whilst growing up. Such differences between participants and myself could function to facilitate the research process by opening up my curiosity or hinder the process due to me being outside of the experiential world of the participants.
My interest in the impact of illness on family members arose when I worked within health psychology with adults prior to starting clinical psychology training. Working in a clinic with an individual focus made me curious regarding the impact of the service user's experiences on their family members. Furthermore in my first year of training I became familiar with the concept of adversarial or post-traumatic growth with children who had experienced illness themselves. Throughout my experiences whilst a trainee I have been exposed to dominant discourses around pathology and deficits. Therefore within the current study I have attempted to move away from merely replicating and propagating such discourses around the impact of 'caring' on young people and expand on the existing literature concerning resources, resilience and growth.

2.6. CRITERIA FOR EVALUATING QUALITATIVE RESEARCH

The epistemological differences between quantitative and qualitative research methods render much of the existing criteria used to assess the quality of quantitative research unsuitable for qualitative studies (Elliott et al., 1999). However, Elliott et al. (1999) have developed guidelines that encompass both criteria relevant to all research and more specific guidelines for evaluating qualitative methods. I have summarised below how this study aims to meet Elliott et al.'s (1999) criteria to ensure quality.

2.6.1 Owning One's Own Perspective

Through the inclusion of the reflexivity section, an attempt has been made to offer the reader a glimpse into some of the beliefs, values and theoretical assumptions that have informed the researcher. It is anticipated that this will allow the reader to consider the data and interpretation from their own perspective, whilst holding in mind the lens through which the researcher saw the data. Furthermore a reflective journal was kept throughout the research process to allow the researcher to reflect upon the influences on their understanding, which may have led to the
privileging of certain information and these issues were also discussed within supervision.

2.6.2 Situating the Sample

The demographics illustrated in Table 1 will allow the reader to evaluate who the findings of the study might be relevant to.

2.6.3 Grounding in Examples

Central to grounded theory is the grounding of the constructed theory in the data (Glaser & Strauss, 1967). The included appendices reflecting the data analysis endeavour to make the analytical process transparent, whilst throughout the findings, examples are used to illustrate the categories.

2.6.4 Providing Credibility Checks

A grounded theory sub-group of a qualitative research group at the University provided a forum whereby transcripts were read and discussed and coding was conducted and compared by other trainee clinical psychologists. This offered the opportunity to explore some of the constructed codes and categories, and also to discuss issues of personal perspective to facilitate recognition of this influence on the theory being constructed. Furthermore, the University supervisor monitored the analytical process by reading three of the transcribed interviews and commenting on the line-by-line codes, focused codes and categories.

2.6.5 Coherence

The use of grounded theory method to construct a coherent theory integrating and synthesising different elements of the participants’ accounts of their lived experiences is intended to aid understanding for the reader. Moreover, it is hoped
that the verbal narrative accompanying this model further elaborates and extends the descriptions and relationships presented.

2.6.6 Accomplishing General versus Specific Research Tasks

The aim of the current study was not to construct an over-arching theory, generalisable to all young people who live with a family member with a chronic illness or disability. Rather the study aimed to construct a portrayal of the experiences of a number of young people facing this experience. Theoretical sampling was a technique used to further develop and extend understanding of the experience in an attempt to thicken the emerging theory. Furthermore, the current study aimed to offer participants the opportunity to voice an alternative to the dominant rhetoric that portrays ‘young carers’ as victims with unpromising futures.

2.6.7 Resonating with the Reader

The study was written up with the participants in mind and therefore aimed to capture their experiences from their own perspectives. It is therefore hoped that the way the findings have been reported will resonate both with young people who live with a family member with a chronic illness or disability and professionals who might have the opportunity to work with them.
3. FINDINGS

3.1. INTRODUCTION TO FINDINGS

The findings section is structured according to categories in order to present a detailed description of the emerging central concepts. However, although this presentation might appear sequential and orderly, this does not reflect the interactive nature of the categories and concepts within them. Each category is described by expanding on the focused codes within them, and statements direct from the transcripts are quoted to illustrate codes and categories. The categories represent a rich wealth of information taken from the transcripts and it would certainly be possible to approach the findings from a number of positions or perspectives. However, as the focus of this study is on the occurrence and process of adversarial growth in young people affected by family illness or disability, discussion of the findings is focused around such areas in an attempt to address the research question. A diagrammatic representation of the relationships between the categories, with additional explanation can be found at the end of this section.

3.2. CATEGORIES

From the analysis, six higher-level categories and ten lower-level categories were generated to synthesise and illustrate the focused codes. These categories are presented in Table 2.
Table 2: Grouping of Focused Codes into High- and Low-Level Categories

<table>
<thead>
<tr>
<th>HIGH-LEVEL CATEGORIES</th>
<th>LOW-LEVEL CATEGORIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Illness Experiences</td>
<td>Understanding</td>
</tr>
<tr>
<td>Other Life Crises</td>
<td>Coping Efforts</td>
</tr>
<tr>
<td><strong>Factors Promoting Growth</strong></td>
<td>Social Support</td>
</tr>
<tr>
<td>Growth</td>
<td>Personal Qualities</td>
</tr>
<tr>
<td></td>
<td>Relationships</td>
</tr>
<tr>
<td></td>
<td>Religion</td>
</tr>
<tr>
<td></td>
<td>Future</td>
</tr>
<tr>
<td>Challenges</td>
<td>Life Lessons</td>
</tr>
<tr>
<td></td>
<td>Negative Impact</td>
</tr>
<tr>
<td>Identity</td>
<td>Responsibility</td>
</tr>
</tbody>
</table>

### 3.2.1 Family Illness Experiences

Each individual shared their own narrative of their experiences of family illness and caring. These narratives held within them idiosyncrasies particular to individual’s experiences, to positions within the family (e.g. as a sibling or a child of the person who was ill or disabled) and to the disability or illness affecting the family. However, commonalities of experience were also expressed.

The process of discovering the illness or disability and receiving the diagnosis was described. Some participants had siblings or parents who were ill before the participant’s birth, so they had never known life differently, whilst for others their relative became ill during their lifetime. For each individual there was a process of
realisation or discovery of the illness and its implications for themselves, their relative and their family.

For a number of people, the impact of the initial discovery of family illness or disability produced a shaking of the stability of their everyday lives. The changes produced by the illness that required accommodation and adaptation by individuals and families, initially resulted in a more chaotic and unstructured experience of day-to-day life.

_It was a bit when my mum did fall ill – very hectic._ (Kwame, aged 19, mother had a stroke)

Coming to terms with a number of challenges posed by the disability or illness, such as communication difficulties, medical treatments and society’s response and often prejudice to disability formed part of individual’s narratives about life with family illness or disability. Similarly the experience of living with relapse and recovery for people whose relative had a chronic illness posed its own unique challenges of managing raised hopes and disappointments.

_Umm and then she had some radio- and chemotherapy and then she turned out just fine…..um after about two years ago she found out she's got cancer again._ (Natalia, aged 16, mother has cancer)

However, following the chaos and disruption of adjusting to life with family illness or disability came more stability. Participants described the importance of ‘getting on with life’, particularly in relation to caring routines, school and social life.
All these things happen and you've got to ignore them and live life (Nina, aged 17, lives with brother with developmental delay)

I think I've done really well to be honest. But I don't really see it as a challenge then if you know what I mean. It's just how things are. (Jenny, aged 16, lives with brother with autism)

However, encountering ignorance regarding disabilities within society still interrupted some individual's attempts at getting on with life. Furthermore, often related to other people's lack of understanding about illness and disability and subsequent reactions, ensued the decision whether or not to disclose family illness to others.

It's like if I go out with my mum or something and she's deaf, they'll non-stop apologise for ages. And then they treat us like we're not able to do anything, which I don't like. (Anthony, aged 17, mother is deaf and brother has spina bifida)

my friend was like "I didn't know he had Down's Syndrome" and I was like "I didn't know it was an issue" and she was like "oh yeah I suppose actually" and I said "you know it's not an issue because I don't make it one". (Gemma, aged 16, step-brother has Down's Syndrome)

3.2.2 Other Life Crises

At the same time as caring for their family member, a number of individuals were also experiencing other stressful life events, such as personal health problems, other relative's ill health, parental separation, assaults on family members and bereavement.
It's actually it's kind of ironic cos err my dad actually suffered a heart attack three months ago (Kwame, aged 19)

I went through quite a hard time when my grandmother passed away. (Nina, aged 17)

Some of my friends have committed suicide (Angel, aged 19)

Drawing on experiences of coping with adversarial situations was considered to aid self-efficacy in coping with future challenges. For example, Kwame described how he used the experiences he went through when his mother had a stroke to help him manage the additional distress and responsibilities he faced when his father had a heart attack.

I kind of used the previous situation with my mum to come up with the situation with my dad basically (Kwame, aged 19)

Participants commented that these other challenging life circumstances led to growth and interacted with the positive psychological changes they attributed to their caring experiences. For example, when speaking about the death of her grandmother, Nina said:

And I remember on bonfire night thinking "why are people celebrating", do you know what I mean? Stop the fireworks. But I was quite sad at the time but I've moved on from it and it's helped me grow. (Nina, aged 17)

The cumulative effect of crises was discussed as challenging in itself, as in isolation adversarial events might have been more manageable.
so it's that added with all of life's other complications (Ewan, aged 17, sister has Rett's syndrome)

just seems like one thing after another sort of thing just making it harder and harder. (Elizabeth, aged 17, brother has epilepsy and autism)

Furthermore, Angel talked about how her experiences of multiple bereavements in particularly tragic circumstances had led to a negative impact of sensitivity to and fear of loss:

not long after my dad died my friend died as well and er it's just really affected me so I'm always careful with people. I'm always like "are you sure you're alright?" cos especially as some of my friends have committed suicide I've been like "are you ok?" (Angel, aged 19)

3.2.3 Factors Promoting Growth

Understanding

The illness or disability of a relative was explained as a difficult situation to comprehend initially. Participants' ages at the development of the illness or disability made it even more difficult to develop an understanding:

I was very upset cos he got cancer when I was only five and the way they explained it to me was I needed, it was enough that I needed to know. But I didn't understand much at that age. (Angel, aged 19, father had cancer)

Some participants described age as being an important influence in the development of their understanding of their relative's illness, whilst for others the progression of time was seen as significant. In particular, time seemed to lead to a
distancing from the initial impact of the situation and in turn followed a process of acceptance and adaptation.

Um it was probably about when I was when I started school probably. When I was about four or five. That I started to realise things weren't quite right (Jenny, aged 16, was three years old when her brother was born with autism)

it happened kind of a while ago, I've had time to look back and reflect upon it. That's definitely helped as well cos I mean if it'd happened last year I'd still be a bit you know bemused by the whole situation, but because it happened a while back it's kind of like I've seen where it's changed me and like moulded me so to speak. (Kwame, aged 19, mother's stroke was five years ago)

Throughout the duration of the illness or disability a number of participants made reference to making sense of their situation and finding meaning within it (for example through religion or relationships), both of which seemed to be active processes resulting in enhanced understanding.

Coping Efforts

Participants referred to different ways they managed the difficulties associated with family illness or disability, as well as accessing social support and making sense of their situations. A number of participants referred to the need to 'cope' with the situations and continue with life as usual:

I've tried my best not to let the situations get the best of me. (Kwame, aged 19)

Try to cope with everything even if it's really hard sometimes. Just try to carry on as normal, even if it's really difficult. (Natalia, aged 16)
The importance of acceptance and adaptation to the situation was discussed. Both problem-focused and emotion-focused methods of coping were described. For example, Elizabeth described information gathering as a helpful strategy, whilst Natalia talked about keeping her emotions to herself and crying in private as a means of release. Remaining positive and holding onto hope and optimism seemed important for some people, as Sally explained:

_Umm I've just sort of got to a point where you either cry all the time or you laugh all the time sort of thing and if you focus on all the bad points in life and yeah my dad's alcoholic, I don't really get along with mum and this this this and that that that and then you're going to be upset all the time and I don't like being upset. I like to be happy. So I sort of think I look to my future and I look to see where I want to be and what I want to do with my life._ (Sally, aged 17, father misuses alcohol)

A number of participants used downward social comparison, whereby they compared their relative's condition with other people who had more serious difficulties, in order to view their own situation as less challenging:

_You know it doesn't make a different to me. I think it's because it's not really that a severe case._ (Gemma, aged 16, step-brother has Down's Syndrome)

Kwame, Anthony and Natalia explained how coping with their current experiences had also helped them in managing other challenging circumstances as they arose.

_Social Support_
The importance of social support emerged during the interviews. Social support from family and friends was described as important in managing negative emotions, offering practical help and providing reassurance:

*family were constantly coming round, saying "she's going to be fine", cooking us food. Cos obviously my mum was the main, is the main cook of the house and when she was out for a little bit she couldn't do that and um. So yeah, definitely close friends and family helped.*  
(Kwame, aged 19)

*one school friend I don't know what I would do without her. As in she's really helped me through everything..... Emotional support definitely. Like she's always been there for me*  
(Nina, aged 17)

However for some participants, adopting a caring role within a family seemed to also raise barriers to accessing social support. Angel discussed how her role as an 'agony aunt' within her peer group and family (which she believed stemmed from her experiences with her father) made it difficult for her to gain support when she needed it:

*I end up solving everyone's problems and then my problems get pushed aside and no one really talks to me when I need them.*  
(Angel, aged 19)

Furthermore a number of participants discussed how they perceived their parents as unavailable for support due to the stress of the family illness:

*But you’ve got to be strong for your parents because they don’t want to have the, to have to cope with you as well as what’s going on.*  
(Angel, aged 19, father had cancer)
Participants who attended a Young Carers Service commented on the importance of universality, that is the normalising effects of meeting others in the same situation, and described valuing opportunities for respite and general support.

3.2.4 Growth

Personal Qualities

Through the process of caring for a family member individuals experienced an enhancement in a variety of qualities and personality characteristics that were deemed positively. These characteristics fell within the realms of both intrapersonal and interpersonal qualities.

Interpersonal qualities such as an increased ability to empathise with others, the development of a non-judgemental attitude, enhanced appreciation and valuing of others and life, and a more thoughtful outlook were both shaped by and subsequently informed relationships. So for example, Gemma described how receiving her step-brother’s diagnosis of Downs Syndrome led to her family pulling together and to her developing a greater appreciation of her other relationships.

*I just think you know you value, you value your family when you’re in a situation like that because obviously there are going to be days when it’s hard, but you have to get through it because at the end of the day you have each other* (Gemma, aged 16)

Furthermore, enhanced qualities at a more intrapersonal level also occurred. A number of individuals described an enhanced sense of personal strength developed through survival of the difficult experiences they faced. Additionally increased maturity had been noticed by participants themselves and others around them:
I think it's helped me to grow up and become more mature. And I'm glad really (Nina, aged 17)

Independence was also described in some circumstances as a positive personal quality developed through the experience of living with family illness, which had positive implications for individual's futures:

I think it's quite a good thing though because I like...I can't think of the word...I can do more stuff for myself and if I wanted something I can go out and do it. (Anthony, aged 17)

Relationships

Family illness or disability inevitably led to role redistribution within families, often where the ill family member's roles were shared out between others to alleviate the burden:

It's like we've got our roles at home, everyone's doing something, a little something instead of like making my mum to do it. (Natalia, aged 16)

However, family relationship roles also shifted from how they had been previously, as the distinction between 'mother-daughter' or 'brother-sister' became subtly different with the process of disability or illness.

he sees me like a second mother (Nina, aged 17, brother has developmental delay)
Before we were like, our relationship was like mother and daughter. It was pretty much like, we didn’t treat each other as friends. It was just purely mother and daughter relationship, but now we can actually see each other as friends because she’s telling what she thinks, how she feels. And I learned that I can do the same. (Natalia, aged 16)

Often related to these relationship role shifts was an enhanced sense of closeness between participants, their relative and their wider family:

with my family we’ve got closer. I would say we’ve become more of a unit, whereas before we were all doing our own thing but now we’ve definitely become a unit. (Kwame, aged 19)

I think everyone got because of my mum being ill, everyone actually realised that someday she might not be here so we should get closer to her and have a better relationship with her. (Natalia, aged 16)

Alongside increased closeness was a greater appreciation of individuals and the value of family.

I just think you know you value, you value your family when you’re in a situation like that because obviously there are going to be days when it’s hard, but you have to get through it because at the end of the day you have each other and I think that’s important (Gemma, aged 16)

Some individuals also commented on viewing their family member who was ill as a role model and saw their own life and talents as attributable to this person for which they were appreciative:
I love my dad. And I learnt so much from him. Everything I know today is because of my dad. (Angel, aged 19)

This seemed to relate to reciprocity within relationships, whereby the young person was caring for their relative, but also gaining a lot in return:

It's kind of like the theory that um my mum and dad have added value to me. So the way I see it is that I have to um when I graduate and get a very good job I take care of them. As a kind of reward for them taking care of me. (Kwame, aged 19)

Finally, participants described the personal qualities they have developed through their caring experiences as enhancing their relationships:

I just find it easier to make friends and stuff. People see me as an all round better person. (Ewan, aged 17)

Religion

Religion appeared to be important in terms of both promoting growth and being part of growth, specifically for participants in the current study from non-White British ethnic backgrounds. Natalia described how receiving her mother's diagnosis led to a sense of injustice and shaking of her religious beliefs and faith. However over time Natalia described how she sought and found meaning for her mother's cancer and within her religion's teaching that 'everything happens for a reason'. Natalia explained how this helped her to regain her faith.
at the beginning when my mum got cancer the first time I was really upset about it. I was asking God "why my mum, why me, why does it always, well not always, but why does it have to err be us?". And at the beginning I didn’t really I was like ahh ok if God lets us, lets me suffer like that I’m not going to believe in him. I was pretty angry. But then after all thinking I was like maybe it’s true maybe everything happens for a reason. Maybe it will turn out that somehow in my life it will turn out as a good thing. (Natalia, aged 16, Christian)

Nina and Kwame also described how they and their families found meaning within the notion that ‘everything happens for a reason’ and how their experiences had strengthened their faith.

After a I dunno so-to-speak famine there’s always going to be a feast afterwards is the way I see it. (Kwame, aged 19, Christian)

Nina talked about the need for maintaining hope, which she and her parents found by turning to Islam.

my parents just turned to religion you know just became more optimistic and it helped them move on. (Nina, aged 17, Muslim)

Future

Participants acknowledged the likely impact of their caring experiences on different aspects of their futures. One particular aspect related to chosen career. Sally, Elizabeth and Nina spoke of their plans to work in the caring professions and attributed their decisions to their family experiences:
Well I'm thinking of going into social care kind of work cos social services, well they've helped us in many ways but in other ways they've been a bit rubbish so I might sort of help them. (Elizabeth, aged 17)

Sally described how her expertise by experience would aid her abilities to empathise with others as a social care professional:

if I went into social work I could um sympathise with the people and empathise with the people just because I could have been there just because of the different situations I've had to go through. Sort of things, so I think it would be a benefit towards future life sort of thing. (Sally, aged 17)

Conversely Ewan and Anthony used their experiences to decide against a career within the caring professions.

I know I definitely don't want to go into social care... It's just that kind of I don't want to look after other people's human reactions and stuff. (Ewan, aged 17)

Other aspects of careers affected by family illness appeared to be financial, as some individuals felt a financial responsibility to provide continued care for their family member, which spurred them to strive for a well-paid job.

The future responsibility for looking after family members extended beyond a financial commitment. For siblings particularly, the prospect of becoming a full-time
carer for their sibling when their parents were no longer able to was a pertinent issue.

*I'll have to be looking after him for quite a while. Especially like if my parents die before he does. Or like if I have to pay for a care home or whatever, but that's just life.* (Elizabeth, aged 17, lives with brother with epilepsy and autism)

Another aspect of the future related to the way caring experiences prepared individuals for future family roles:

*I mean with regards to me learning how to look after someone and care for someone umm I think definitely I will be a I will be a good husband um I think I'll be a good father as well.* (Kwame, aged 19)

Sally also described how she has used her experiences with her father as a motivating influence to push herself to succeed in life:

*all the things that I've been through as well as like, as well as looking after my dad it's sort of inspired me to err be the bigger person to succeed at, even though I've been through all that I'm still going to get out of it I'm still going to do something with my life* (Sally, aged 17)

### 3.2.5 Challenges

*Life Lessons*
The experiences of living with a family member with a chronic illness or disability provided the ground for learning a number of 'lessons' about life, which were sometimes experienced as quite challenging to take on board.

*I think it's opened my eyes a lot more* (Nina, aged 17)

*But it's kind of made me see how difficult life is* (Kwame, aged 19)

However, despite the challenges involved in learning these lessons at an early age, some individuals commented on the associated benefits.

*when you sit down and you talk about it and you think about it you're like “God yeah a couple of years ago it was all so simple”. But I wouldn't be without it really.* (Gemma, aged 16)

*it's good life experience thing to have* (Angel, aged 19)

At the time an individual's parent or sibling became ill, a number of participants described questioning ‘why me?’ and becoming aware of the unfairness of life. At the same time the transience or fragility of life was also being noticed by participants.

*To capture life. Don't let it go, but don't think nothing's ever going to happen..... Just to make the most of everything* (Angel, aged 19)

Sally, in particular commented about how her efforts in caring for her father had not been noticed or valued, and related this to a wider cultural phenomenon:
I just see that as a part of life. People won't, people always see the bad in other people instead of the good (Sally, aged 17)

Other life lessons, such as practical skills were challenging in different ways:

I've had to learn how to cook, I've had to learn how to get up, I've had to learn how to take responsibility. And although it's not nice to have to grow up quickly because you're supposed to enjoy your childhood, but I think in the future it's a good thing cos I can I don't have to learn it now I can already do it. (Sally, aged 17)

Negative Impact

Alongside the aspects of growth and positive changes reported by people in relation to living with their family member, distress and a number of negative changes were also described.

I've got my ups and downs. It's sometimes it's been really hard for me seeing her suffering and crying because of pain and yeah it has been quite hard (Natalia, aged 16, mother has cancer)

it's not nice to have to grow up quickly because you're supposed to enjoy your childhood (Sally, aged 17, started caring for her father aged 5)

Educationally, a number of challenges were discussed. Falling behind at school academically, being bullied in relation to the relative with a disability and facing disbelief from teachers as to difficulties within home life were all experiences expressed by the participants.
my little brother doesn't actually let me study that much. And the thing is I feel bad if I go to school, come back and go straight to my room (Nina, aged 17)

kids in middle school — so cruel. And like "oh you don't have a dad" or they play on it and be horrible (Angel, aged 19)

Furthermore social lives were sometimes restricted either due to practicalities of having a family member who was ill or disabled and the additional work entailed or, as Jenny described, due to closeness with the person and a desire to spend more time with them:

I mean sometimes like a friend wants me to go out and I will be like "no I want to stay in with [brother]" (Jenny, aged 16)

Elizabeth, Anthony and Angel described difficulties within family relationships that they attributed to the presence of disability or illness within the family. For Angel and Anthony they felt their relationships with their parents were not as close as they might have been due to the focus of attention being elsewhere. Whilst Elizabeth saw the stress of having a child with a developmental disability as a factor in the breakdown of her parents' marriage:

I think one of the main reasons why my dad left was because of my brother. (Elizabeth, aged 17)

Responsibility

In their descriptions of the caring tasks they undertook, a number of individuals described substantial responsibilities, which increased with age. Responsibilities
appeared to fall within different domains, such as caring for the relative, providing future care, caring for others and financial responsibilities.

cos I'm the oldest in the house I had to kind of take the man role, organising the household, the shopping, visiting him, making sure he's got his right materials and stuff
(Kwame, aged 19, has two younger siblings)

Some participants felt burdened by the responsibility they faced:

he would expect me to do the washing, the cleaning, the cooking, the washing up. Everything. Make sure everything was neat and tidy and if it wasn't then he'd have a go at me or snap at me sort of thing. Um and then it got to a point where I just couldn't take it any more (Sally, aged 17)

you have to, you feel more like responsible and it's less enjoyable (Anthony, aged 17)

It gets very pressurey sometimes. Very pressurey. (Angel, aged 19)

However the same individuals also recognised benefits, such as increased autonomy and developed skills as part of that responsibility.

I think it's quite a good thing though because I like...I can't think of the word...I can do more stuff for myself and if I wanted something I can go out and do it. (Anthony, aged 17)

There was also a sense amongst some people that responsibility was not forced upon them.
I can’t really see me having to do anything that I don’t want to do. (Jenny, aged 16)

However, even when responsibility was not explicit, Sally, for example described her guilt at not doing more for her father and felt responsible for his condition not improving. Furthermore, Anthony described how the general public located responsibility for his mother and brother with him when they were all out together due to ignorance regarding disabilities.

3.2.6 Identity

A number of different issues relating to a person’s ‘identity’ or ‘sense of self’ emerged from participant’s narratives. Participants described themselves as changed in some positive way as a result of their experiences:

*People see me as an all round better person.* (Ewan, aged 17)

*It definitely made me a stronger person* (Natalia, aged 16)

This changed identity incorporated a number of the personal qualities and lessons learned identified by participants. It therefore seemed as though people saw their identity as developed and shaped rather than shattered and reconstructed through their experiences and it is noteworthy that a number of individuals made direct links between these changes and their experiences.

*how I’ve changed has coincided with what occurred with my mum.* (Kwame, aged 19)
There also seemed to be a sense amongst some people as their changed 'self' being noticeably different from their peers as a consequence of their experiences:

*I have been told that um I'm 19 and as a black male I'm very different to other 19-year-old black males that you see. I've been told on a regular basis that. I mean I guess I can kind of see it myself as well to be very honest (Kwame, aged 19)*

*I used to find it quite difficult at first because I remember when my brother was first born when I used to go to parties and things it used to be family parties where the adults were with the adults and the kids with the kids.... And I didn't really fit in. (Nina, aged 17)*

There also seemed to be a desire for individuals to be seen:

*more for like who I am (Nina, aged 17)*

rather than as a 'young carer' or person affected by family illness. This seemed to contrast with the recognition of valued aspects of identity gained from caring experiences (e.g. being a stronger, caring person).

Finally, there was a sense of the process of integrating a person's experiences into their sense of 'self' or identity.

*I've had time to look back and reflect upon it. That's definitely helped as well cos I mean if it'd happened last year I'd still be a bit you know bemused by the whole situation, but because it happened a while back it's kind of like I've seen where it's changed me and like moulded me so to speak. (Kwame, aged 19)*
For some people this appeared to be a social process, as Sally described making sense of her experiences and their effects on her identity through talking to people about them:

*because I've gone through it so many times before that I already know that it's in my mind and it's part of my life.* (Sally, aged 17).

### 3.3. RELATIONSHIPS BETWEEN THE CATEGORIES

Having identified six higher level categories, the relationships between them were considered. Figure 1 is a diagrammatic representation of the categories and connections between them.

**Figure 1:** The Theory of Adversarial Growth in a group of Young People Living with Family Illness

In a more realist grounded theory approach, the category 'Growth' might be referred to as a 'core category' (Willig, 2000). However, from a social constructionist
grounded theory approach the categories that have emerged are considered to be contextual, that is constructed between the participants and researcher and hence situated temporally and culturally. Thus in a different construction of the data, a different category altogether might form the basis for the developed theory.

Both family illness experiences and other life crises that were experienced by the participants simultaneously gave rise to factors promoting growth and challenges. For example, family illness experiences and life crises led to attempts to make sense of, access social support in relation to and cope with these occurrences.

3.3.1 Factors Promoting Growth

Understanding seemed to be enhanced by coping efforts and social support, whereby accessing social support and making attempts to cope with the situation led to an improved understanding of a person's situation.

Coping efforts were also related to responsibility, as this provided one of the core challenges for a young person facing family illness or disability to handle. The process of accepting and adapting to their situation led many young people to develop certain personal qualities, considered an area of growth. Religion appeared to be both a growth sphere, but also people turned to religion and spirituality in order to help them cope.

Social support shared a bi-directional relationship with coping efforts, as people accessed social support as a way to cope and social support enhanced coping. Social support was also closely linked to relationships, as accessing support from friends and family led to enhanced closeness and appreciation of those relationships.

3.3.2 Growth

Relationships with other people both enhanced the personal qualities developed by individuals, and qualities led to improved relationships. The development of an array of personal qualities led people to consider how their futures would be affected
by such qualities, for example, being more caring making a person define their future self as a good father. It is clear from this example how a sense of developed personal qualities were incorporated into a changed awareness of ‘identity’ or sense of self.

Relationships also influenced future concerns, as people anticipated important people they shared relationships with as being role models for how they would like to be in the future and also expected increased closeness with their family in future.

Religion helped people to find meaning in their situation, as represented by individuals who commented that their religious beliefs help them to understand that ‘everything happens for a reason’. Furthermore, religion gave people hope, which enhanced their feelings of self-efficacy in coping with the situation.

Individuals’ futures were affected by the personal qualities they had developed, their significant relationships and also the life lessons they had learned through their experiences. For example, in relation to the life lessons regarding the transience of life, people spoke of making the most of the opportunities they were presented with in their future families and careers.

3.3.3 Challenges

The challenges faced by people experiencing family illness and other life crises also mediated the relationships between these experiences and growth and these experiences and identity.

The lessons learned about life had implications for individuals’ futures in terms of practical skills they had acquired and also issues surrounding making the most of opportunities, as described above.

Struggling to come to terms with negative impact of family illness experiences and other crises led to the development of certain personal qualities. In turn these personal qualities had implications for identity, for example, having survived the negative impact of experiences led to awareness of qualities such as inner strength and determination, which consecutively led to a sense of the self as a ‘strong person’.
In a similar way, responsibility led to enhanced qualities such as autonomy and independence, and hence affected an individual’s future and identity.

3.3.4 Summary

In summary, the relationship between adversarial events (family illness experiences and life crises) and growth was mediated by factors promoting growth and challenges. Furthermore, the relationship between adversarial events and identity was itself mediated by growth and challenges. Within the relationships between these conceptual categories existed a number of other significant connections between low-level categories and focused codes.
4. DISCUSSION

This section presents a discussion of the broad findings of the current study with regard to existing research and theory. The implications of these findings in relation to clinical practice and future research are considered and the limitations of the current study are discussed.

4.1. ADVERSARIAL GROWTH IN YOUNG PEOPLE EXPERIENCING FAMILY ILLNESS

4.1.1 Growth

The findings suggested that for the participants in the current study, adversarial growth was not only a phenomenon they recognised and experienced, but also felt was important to them. However, growth was related to other challenging events in a young person's life, as well as to their experiences of family illness or disability. Individuals described growth in areas of personal qualities and characteristics, relationships, religion and the future. These areas all fall within the domains identified by Tedeschi and Calhoun (1995; 1996).

In relation to intrapersonal qualities, reports of increased personal strength, maturity and independence were observed. Tedeschi and Calhoun (1995) state that a commonly cited growth area in individuals who have faced difficult experiences is a greater sense of personal strength and self-reliance. Tedeschi and Calhoun (1995, p.13) comment on how "the crisis can set in motion the need to meet a wide array of specific demands and meeting these successfully can greatly enhance the individual's personal strength". As a result of facing these demands, individuals therefore draw a conclusion that they are stronger and this confidence in coping with difficult situations generalises to other spheres. Interpersonal qualities developed through coming to terms with family illness or disability included empathy, non-judgementalism, thoughtfulness and greater appreciation. Participants described how these qualities were both learned via and also affected their relationships with others, in particular their family member who was ill or disabled. In research with trauma survivors, increased compassion, empathy and improved sensitivity to
other's perspectives, needs and feelings have been noted (Collins et al., 1990). Tedeschi and Calhoun (1995) frame these growth areas in terms of a changed sense of relationships with other.

In the current study a category of relationships emerged, in which issues related to enhanced closeness and intimacy within relationships, appreciation, reciprocity and role redistribution within families. Again, Tedeschi and Calhoun (1995; 1999) have commented on the transformative effects of challenging life circumstances on intimacy within relationships and described an increased sense of appreciation for both life in general and significant relationships. It has been noted that role redistribution is a common coping mechanism in families with an ill or disabled member (Pederson & Revenson, 2005). In the current study, however, this did not seem to be simply a way of ensuring roles and responsibilities within the family were fulfilled, but also a way of transforming relationships within the family and enhancing closeness between family members.

A number of people in the current study viewed religion as both a facilitating agent in positive change and an element of growth itself. Growth in the domain of spirituality forms part of Tedeschi and Calhoun's (1995) model, as existential questions confront individuals facing challenging events. Janoff-Bulman (1992) interpreted the question of "why me?" as representative of shattered schemas regarding benevolence and meaningfulness in the world, leaving individuals without a 'roadmap' for comprehending their world and their place within it (Tedeschi & Calhoun, 2004). As religion can offer purpose and meaning in life (Calhoun & Tedeschi, 2006), religious beliefs and teachings can act as a context to help people make sense of and find meaning in the challenging situations they encounter. For participants in the current study who commented on issues of spirituality, not only did their religion help them find answers to questions such as "why me?", but their faith strengthened as a result of engaging in a search for this meaning.

The current study's identification of future as an element of growth resonates with Tedeschi and Calhoun's (1995) domain of the 'emergence of new possibilities in life'. A number of participants described how their experiences had shaped their decisions about their future careers and also about their preparedness for parental roles. However, a number of participants in the current study also had future
possibilities shut down for them, as the nature of a chronic illness or lifelong disability also generated lifelong responsibilities. In this way, it seems as though the experiences of young people facing family illness do not fully fit with the concept of adversarial growth, as the model does not account for the possibility that adversarial experiences might be chronic in nature rather than isolated traumatic events.

It is noteworthy that the positive psychological changes described by participants in the current study bear significant resemblance to those reported by adult carers in a study by Pakenham in 2005. He also reported personal growth, strengthened relationships, greater insights into hardship and greater appreciation for life. Furthermore, Banks et al.'s (2001) study which looked at parental reports of benefits gained by their children when caring for a relative included positive growth outcomes in practical skills, family relationships, independence, and understanding of disability. These elements of growth were also reported by young people themselves in the current study.

### 4.1.2 Factors Promoting Growth

Having ascertained that elements of adversarial growth were experienced and reported by young people participating in the present study, it is important to consider the influences that appeared to mediate the relationship between family illness experiences and growth. These influences were termed ‘factors promoting growth’ and included understanding, coping efforts and social support. It is noteworthy, that in their model of adversarial growth, Calhoun and Tedeschi (1999) specify that it is not the traumatic event itself that leads to an individual’s experience of growth, but rather a struggle to come to terms with that event.

Participants’ narratives included a sense of their everyday lives being disrupted by their relative’s illness or disability and a ‘chaotic’ period of life ensuing. Within this chaos was a need to come to terms with the illness or disability, which was challenging in itself. Janoff-Bulman’s (1992) social cognitive model of trauma responses, which proposes that traumatic events shake an individual’s set of assumptions about the world, seems fitting with these descriptions. According to Janoff-Bulman (1992) assumptive worlds allow people to make sense of what
happens to them and guide their actions, hence disruption produces significant distress and the need to rebuild one's view of the world. Participants described a process of adaptation and acceptance to their family illness experiences, which required time and developed with age.

The factors promoting growth identified could all be considered as coping mechanisms in some form. Finding meaning and making sense of the illness or disability, accessing social support and finding ways to manage intense emotions and adapt to the situation all helped the individuals in 'coming to terms' with their situation. This finding supports Tedeschi and Calhoun's (1996) emphasis of the need for engaging in initial coping responses to manage distress before any form of growth can take place. It is therefore possible that engaging in these processes laid down the foundations for growth to occur for the participants.

A particularly distinctive way in which individuals coped with and made sense of their situation was through the use of downward comparisons, whereby they compared themselves with others who were perceived as less well off (Festinger, 1954). The cognitive process of downward comparison is thought to be a particularly helpful coping strategy for people experiencing difficulties that cannot be easily resolved (Wills & Sandy, 2001), such as family illness. The use of downward comparison has been found to result in improved self-esteem and reduced symptoms of anxiety and depression for individuals coming to terms with life crises or trauma (Tedeschi & Calhoun, 1995). Therefore it is possible that engaging in this form of cognitive processing offered people hope and allowed them to normalise their experiences.

Due to the difficulty in initially comprehending the illness or disability of a relative, making sense of and finding meaning in the situation seemed particularly important prior to any experiences of growth. This observation appears congruent with Calhoun and Tedeschi's (2006) model, as they stress the importance of cognitive engagement and rumination in establishing a sense of comprehensibility about the event. Two participants specifically commented on 'going over' what had happened to them in their heads in order to make sense of it and the majority of participants reported giving a lot of thought to their situations, although it is difficult to ascertain what form this cognitive engagement took.
Social support functioned as a mediator between family illness experiences and growth, although on occasion it proved difficult for some individuals to access such support when they needed it. According to Neimeyer (2004) sympathetic and helpful responses to disclosure can afford "validation of one's experience and the provision of social support that can facilitate healing and growth" (Neimeyer, 2004, p.54). Furthermore, narration of adverse experiences, such as family illness, with supportive others allows a person the opportunity to begin to reconstruct their schemas into a more comprehensive life story, which will, in turn, influence their sense of self (Neimeyer, 2006). A particularly important finding from the current study was that a number of individuals felt their parents were either unavailable for support or 'should not be bothered' due to the other demands they faced. It is significant that parents are central to adolescent identity development (Grotevant & Cooper, 1985) and constitute the most significant audience for young people's narratives and developing life stories (McLean, 2005). This has implications for the accessibility of other opportunities for social support if parents are deemed unavailable.

4.1.3 Challenges

The challenges faced by young people experiencing family illness mediated the relationship between experiences and growth, and also directly related to issues surrounding identity.

Participants recounted the negative impact of living with family illness or disability, noting the distress, educational difficulties and social restrictions encountered as a result. This finding supported Aldridge and Becker's (1993a) conclusion that young people experiencing family illness have the potential to encounter problems at school, such as bullying and poor academic performance. However, it is of note that all participants who commented on struggling academically found this resolved with time, as they came to terms with their relative's illness. Furthermore, all participants in the current study were attending college, which suggests that they had transcended the initial educational difficulties and were still able to achieve academically. As described above, accessing social
support is important for constructing a coherent narrative of family illness experiences (Calhoun & Tedeschi, 2006; Neimeyer, 2004), hence the social restrictions faced by some young people have potential implications for the incorporation of such experiences into their life story. Finally, in relation to participants' reports of distress associated with their relative's illness or disability, Janoff-Bulman (1992) and Calhoun and Tedeschi (2006) recognise that a degree of distress is a prerequisite for growth to occur. This is because if an event does not produce enough cognitive dissonance to destabilise an individual's schemas and assumptions about the world, there is no potential for cognitive efforts towards rebuilding and reconstructing those schemas (Tedeschi & Calhoun, 1995). Furthermore, reports of continued distress support the hypothesis that growth and distress are not opposite ends of the same continuum and hence can occur alongside each other (Linley & Joseph, 2004).

The category entitled 'life lessons' related to the realisation that life is transient, unfair, and efforts are often devalued. Despite experiencing such lessons as challenging, participants also found benefits within the process of learning. In Janoff-Bulman's (1992) theory, three fundamental assumptions or schemas relevant to trauma were identified: 'the world is benevolent', 'the world is meaningful' and 'the self is worthy'. The life lessons described by participants seem to correspond with the shaking of these beliefs about the world. For example, vulnerability in the context of life's transience and fragility casts doubt on the world's benevolence and predictability. Simultaneously, the occurrence of adverse circumstances such as family illness or disability on undeserved families seems unjust, which can lead to questioning the meaningfulness of the world. Finally, the belief that the self is worthy can be challenged when personal sacrifices and efforts are devalued. The shattering of these assumptions (Janoff-Bulman, 1992) subsequently demands a rebuilding of schemas that incorporates elements of previously held assumptions with new information from the adverse experience (Tedeschi & Calhoun, 2004). The process of this reconstruction can leave individuals feeling stronger and better able to cope in the future with adversity if it should emerge (Tedeschi & Calhoun, 1995; 2004).

The level of responsibility and associated burden faced by young people experiencing family illness or disability varied significantly. This could be seen to be
related to Jurkovic's (1997) distinction between adaptive and destructive parentification whereby inappropriate and excessive responsibilities are thought to be indicative of the latter. In fact, one participant explicitly commented on her experiences of always being the care-giver and never the receiver, which could be considered as illustrative of Bowlby's (1977) definition of compulsive care-giving. However, it is also noteworthy that a number of individuals commented on making the choice to assume responsibility themselves rather than being obliged to take it, and recognised beneficial elements to responsibility for both their current and future lives. These people perhaps concurred with Barnett and Parker (1998) who recognised parentification as an opportunity for developing early competence and hence as preparation for later life experiences.

4.1.4 Identity

A number of different issues relating to a person's 'identity' or 'sense of self' emerged from participant's narratives. It is noteworthy that although the construction of identity can be thought of as a lifelong process, the life story begins to emerge in adolescence, hence issues of identity development are particular salient for individuals at this time (McLean, 2005). In the present study, the notion amongst individuals of their 'self' as changed in some way through their experiences of family illness or disability seemed to predominate. This finding seems relevant to the large body of research that has identified that chronic illnesses have the potential to hold significance for an individual's identity. This is because the illness functions as a biographical disruption (or interruption to the life story), which then necessitates 'biographical work' regarding identity. Asbring (2001) states that this biographical work can include the discovery of lost, remaining and new aspects of identity and a partial identity-transformation (Berger & Luckman, 1979) based on the new situation. The onset of family illness or disability and ensuing developments in roles and responsibilities could therefore be seen as a biographical disruption to the young people in the present study. Furthermore, if this is the case, it is possible that the participants' descriptions of 'self' as somehow different from 'self' prior to family illness represented a form of partial-identity transformation. Pals (2006) elaborates on the earlier discussion surrounding the quest for meaning, by suggesting that
continuously narrating and interpreting past experiences and incorporating them into the life story (narrative identity processing) provides the foundations for (partial) identity transformation. Therefore it is possible for the young people in this study that through interpreting their experiences, including the challenges they presented (e.g. 'understanding') and narrating these in the presence of others (e.g. 'social support') a conclusion about growth was reached, which was incorporated into the person's sense of who they are (e.g. stronger, better, more caring). In fact, this view is congruent with Pals and McAdams' (2004, p.68) assertion that adversarial growth is best understood as an "identity-making narrative process" in which individuals construct a narrative as to how the self has been positively transformed by adversity and integrate this into their identity and life story.

However, it is also important to consider that from a post-modernist perspective, people hold multiple self-narratives (Nochi, 2000). From this perspective, 'identity' is seen as fluid and constantly shifting according to context and relationships (Gergen & Gergen, 1988). Postmodernists, such as Foucault (1988) do not believe that identity is a 'real' entity located within people, but instead that 'identity' is a way of talking about the 'self', a discourse, communicated to others through interactions with them. This seemed particularly relevant to participants description of 'me as who I am' versus 'me as affected by family illness'. It is possible that particular self-narratives were more valued by participants in certain social contexts (such as 'me for who I am' being dominant when with peers, while 'me for being different from my peers' being valued more in a research context).

4.2. IMPLICATIONS FOR PRACTICE

The most striking implication for practice from the results of the study appears to be the need for consistency across the support offered to young people living with family illness or disability. The debate illustrated in the introduction regarding the social model of disability and the young carers movement seems to have constructed a situation whereby agencies are working against each other rather than comprehensively to provide coordinated services to meet all of the needs of young people facing family illness (Newman, 2002). Many of the difficulties encountered by
young people (such as restrictions on education and social lives) could be ameliorated by services provided directly to their relatives, whilst at the same time, individual support, as provided by young carers groups could support the person in coming to terms with the experience of family illness. Although ultimately this situation of services working side-by-side in an integrated manner would be preferred by many within the field, a number of barriers exist, which have thus far prevented it from occurring (Newman, 2002).

The finding that a number of participants felt their parents were unavailable for support echoes Dale and Altschuler’s (1999) assertion that family illness has the potential to overwhelm parents to a degree where they lose some of their sensitivity to their children’s experience. There are subsequent ramifications for where young people living with family illness can access the support that is deemed so important. Although peers were frequently described in the current study as a valuable source of support, disclosure was not always considered possible with peers, or on occasion a lack of understanding acted as a barrier. Calhoun and Tedeschi (1998, p.231) have suggested that people who have been through similar experiences may be “one of the most important sources of new goals and beliefs”, which are a key factor in adversarial growth. This suggests an additional value to young carers groups, whereby young people who have similar circumstances can share experiences. Furthermore, Tedeschi and Calhoun (1995) draw attention to the enhanced legitimacy of accessing support from someone who has been through the same situation. However, at the same time, Kilmer (2006) recognises the importance of adult assistance in the facilitation of cognitive and emotional reappraisal of events. As this is often provided by parents, again young carers services could remain aware of the possibility of supporting this reappraisal process.

Calhoun and Tedeschi (1999) have provided a comprehensive account of ways in which professionals might work with individuals to facilitate adversarial growth. The first stage in this process would be to raise awareness of the concept and possibility of adversarial growth with professionals working with young people experiencing family illness or disability. However, Calhoun and Tedeschi (2004) also remark on the importance of not assuming that growth and benefit finding should be an outcome for each individual facing challenging life circumstances. Nevertheless, professionals can play an important role in both helping young people manage the
distress associated with their experiences of family illness or disability and also in facilitating any positive changes and resources they already possess (Calhoun & Tedeschi, 2004).

4.3. FURTHER RESEARCH

A potential criticism of the current study is that the category of 'identity' was not explored enough within the interviews to thicken the concept and its links with other categories. This category was established later on in the analytic process; hence time restraints precluded further theoretical sampling and saturation of the category. However, the current study did raise some interesting issues regarding 'identity' with young people facing family illness or disability, which would be a fruitful avenue for future research to explore further.

One of the ways adversarial growth was constructed within the current study was as a way in which individuals construct a narrative about how the self has been positively transformed by adversity, which is then integrated into their identity (Pals & McAdams, 2004). However, as adolescence is a particularly significant time for identity development, it would be important to consider what other influences are important in shaping a young person's sense of who they are at this time. Furthermore, as from a post-modernist perspective identity is thought to be fluid and context-specific (Gergen & Gergen, 1988) it would be interesting to consider how young people facing family illness make sense of 'who they are' in different contexts. In particular it would be interesting to observe if any dominant discourses exist within the culture of young carers' groups that support particular narratives about family illness experiences and identity.

4.4. CRITIQUE

4.4.1 Generalisability

Generalisations from the current findings are restricted to the participants involved in the study, and conclusions cannot be extended to other individuals or
contexts (Elliot et al., 1999). However, the aim of the current study was not to construct an over-arching theory, which could be considered generalisable to all young people who live with a family member with a chronic illness or disability. From a social constructionist perspective on grounded theory (Charmaz, 2006) it is recognised that any theory constructed is one version of many possible. The findings from the current study have been constructed as a portrayal of the experiences of ten young people facing family illness or disability and therefore any attempts to apply these findings in other contexts should be carried out with caution.

4.4.2 Methodological Limitations

One of the original tenets of grounded theory was that the data collection and analysis should be conducted prior to the literature review to ensure that codes are constructed from data rather than prior knowledge of theory (Glaser & Strauss, 1967). In the current study a review of the literature was conducted prior to the analysis. However, Charmaz (2006) acknowledges that the demands of research proposals in current academia often renders Glaser and Strauss's (1967) original position untenable. Attempts were therefore made to adopt Henwood and Pidgeon’s (2003) stance of ‘theoretical agnosticism’, assuming a critical perspective towards previous theory. However, the possibility remains that at some time during the research process, existing theory was unintentionally imposed on the data.

A criticism that could be levelled at the way in which the analysis of the interviews was carried out relates to the use of in vivo codes. Many of the initial line-by-line codes used in the analytical process to describe the data were in vivo or substantive codes, rather than being at a higher analytical level of abstraction. Charmaz (2006) comments that novice grounded theory researchers often rely on in vivo or substantive codes, with the resulting theory being more descriptive than theoretical. Despite having used other qualitative methodologies in the past, it is noteworthy that this was the researcher's first endeavour with grounded theory. However the processes of constant comparison and memo-writing allowed the relationships between the codes to be considered (Charmaz, 2006) and in the current
study these processes offered the opportunity to treat the categories more theoretically.

A key limitation of the current study is connected with the lack of respondent validation. As the current study concerned representing accounts of the young people interviewed whilst avoiding enforcing the researcher's own biases and ideas onto the data, it seemed particularly important to feedback this representation to the participants for them to check and comment on (Mays & Pope, 2000). However, when young carers services were initially contacted with respect to asking their services users to participate in the study, a number of the coordinators expressed concerns regarding multiple requests being made of people at different time points. In particular, the idea of contacting people subsequent to their interview to gain their perspectives on the constructed theory was deemed too much work to put onto young people. It was requested that the researcher did not include this as part of the study, hence respondent validation was not obtained.

4.4.3 Sample

It has already been stated that this study did not aim to produce a generalisable theory. However, the implications of heterogeneity within the experiences of participants in the current study merit discussion. It is possible and even likely that the experience of living with a parent who is ill or disabled is different to the experience of living with a sibling who is ill or disabled. This raises potential difficulties in terms of integrating any differences in terms of experience into a unified theory in a way that does not alienate the experiences of any of the individuals who participated. It is possible that saturation would have been more likely or a more coherent theory might have been constructed if participants had have experienced specifically parental illness or specifically sibling illness. However, this was an initial exploratory study to determine if the concept of adversarial growth was even applicable with the population who might be referred to as 'young carers'. To view the findings as diminished somehow due to the variety of experiences and illnesses or disabilities faced by the participants would be to dismiss the commonalities of experience. If the sample had have been narrowed down to
young people experiencing parental illness there would have also been a great deal of variation in the experiences of these participants with respect to chronicity, severity, cure and controllability. Furthermore, it is noteworthy that within the analysis none of the categories that emerged were specific to people who experienced either sibling or parental illness or disability.

4.5. REFLEXIVITY

When I first came across the notion of adversarial growth I found it fundamentally appealing and it stimulated my curiosity. On reflection I believe I identified it as a concept that married both my interest in positive psychology, resilience and well-being with the accounts of suffering, adversity and trauma that I have encountered in my clinical work. Furthermore, I believe it tapped into my own personal beliefs about my need and desire for hope and optimism.

Despite being unsure of how to define my religion, I have been influenced by both Christian and Buddhist philosophies at different points in my life. Hearing Kwame's use of religious metaphor caused me to begin to contemplate the effects of my own exposure to such ideas earlier on in my life to my current professional capacity. Furthermore, it made me wonder if I had been particularly drawn to the concept of adversarial growth partly as a result of these influences.

As I became more engaged in the research I began to wonder whether my own curiosity about adversarial growth had led me to want to see it. This was particularly at a time when the media was highlighting the 'plight' of 'young carers' for an awareness week: presenting very bleak portrayals of the difficulties encountered by young people living with family illness and disability. One particular documentary in which severe negative consequences and neglect were presented left me pondering whether my own research was actually unethical, as by considering experiences narrated by young people through the lens of growth was I inadvertently diminishing the enormous challenges they faced?

However, as I progressed with conducting the interviews, I became aware of the sophisticated manner in which the young people I spoke with crafted their narratives
to include both the difficulties their situations posed interwoven with elements of growth and optimism for the future.

Throughout the course of analysing the data and writing up the research I have been on a narrative clinical placement. This has undoubtedly shaped the way I make sense of adversarial growth, as my understanding has developed from the cognitive processes involved in Tedeschi and Calhoun’s (2004) work to more narrative explanations incorporating elements of the life story and identity.

Being aware of my assumptions and biases throughout the process of conducting the research, and in particular the analysis has allowed me to reflect upon my contribution in constructing the data and the results. Furthermore it has offered me the opportunity to consider how my beliefs, assumptions and ideas shape my own identity as both a researcher and clinician.

4.6. CONCLUSION

The current study employed social constructionist grounded theory to explore adversarial growth in young people living with a family member with a chronic illness or disability. The findings suggest that the participants in the current study did experience growth in the domains established in the literature with other populations. Furthermore, growth developed alongside the negative consequences of family illness and these consequences were deemed necessary in order for growth to occur. The findings also drew attention to the importance of social support, meaning making and coping strategies in laying down the foundations for growth. It would seem pertinent for further research to build upon such findings, particularly in relation to issues surrounding the role of adversarial growth in identity development in young people living with family illness. These findings have implications for practice, particularly for considering ways in which services for ‘young carers’ can provide a context for the facilitation of adversarial growth.
REFERENCES


APPENDICES

APPENDIX I: LETTER GRANTING ETHICAL APPROVAL

Suzanne Gray
Department of Psychology - PsychD
University of Surrey

29 November 2006

Dear Suzanne

Reference: 89-PSY-06
Adversarial growth in adolescents coping with parental illness

Thank you for your submission of the above proposal.

The School of Human Sciences Ethics Committee has given a favourable ethical opinion.

If there are any significant changes to this proposal you may need to consider requesting scrutiny by the School Ethics Committee.

Yours sincerely

Dr Kate Davidson
APPENDIX II: SUMMARY OF ETHICAL CONSIDERATIONS

Informed Consent

Participants will be asked to complete a consent form to demonstrate that they have understood the information in the information sheet and agree to take part in the study. It will explained to the participants that the tape recordings will only be listened to by the principal investigator and her university supervisor, and that the tape recordings will be kept in a secure place at the University of Surrey and will be destroyed after 12 months of study completion. It will also be explained that, if the participant wishes, the tape recorder can be turned off at any time during the interview. Verbal consent will be obtained at the end of the interview to ensure that participants agree to the data being used as part of the research.

Right to Withdraw

On the information sheet it will be made clear that participants have the right to withdraw from the study at any time. This will be reiterated at the start of the interview.

Confidentiality

Participants’ confidentiality and anonymity will be ensured in the study. Participant numbers will be assigned to participants and raw data (i.e. audio-tapes) will be kept in a locked filing cabinet at the University of Surrey. Demographic information will be stored separately from raw data, also in a locked filing cabinet at the University of Surrey. Any identifying information will be removed or altered (i.e. pseudonyms will be used) from the transcripts derived from the audio-recordings, which will be stored on the principal investigator’s personal computer (which is password-protected) in a password-protected file.

The only time confidentiality could not be ensured is if a participant disclosed sensitive information regarding risk of harm to themselves or others in the interviews. Therefore the principal investigator will ensure that she explains duty of care prior to the beginning of the interview, stating that she will treat everything the participant says as confidential unless they say something which worries her (such as something which could put themselves or others at risk) and then she would have to tell her supervisor.
Sensitive Issues

Asking young participants to think about their parent's illness in order to reflect on any possible changes, may also make them reflect on the understandably negative changes that are likely to have accompanied any growth. Every precaution will be taken to prevent participants becoming upset during interviews. It will be very important to sensitively word the questions in the interview schedule and to establish a good rapport with participants. A debriefing period at the end of the interview aims to ensure the young person will not leave feeling distressed or without a plan of action of who to speak to if necessary. In the unlikely event of a participant becoming distressed the principal investigator will use her counselling skills to explore and contain the distress experienced and would stop the interview. With permission she would then find a member of staff at the Young Carers Group who knows the participant well and can support them. If additional support was required participants would be advised to contact members of staff at the Young Carers Group, their GP or other support agencies such as the Childline.

Principal Investigator's Safety

There is a low risk to the principal investigator's personal safety if interviews are carried out in participants' family homes. Therefore the School of Human Science Ethics Committee guidance for undertaking data collection at private addresses will be adhered to. A phone-in system will be used and the university supervisor will be provided with a sealed envelope with the name and address of the participant in, which she will only open if the principal investigator does not phone in at the time arranged.
APPENDIX III: INFORMATION SHEET

Unis

PSYCHD CLINICAL PSYCHOLOGY
DEPARTMENT OF PSYCHOLOGY

Experiences of being a Young Carer: Information Sheet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. If you decide not to take part, or to withdraw at any time, this will not affect the standard of care you receive.

What is the purpose of the research?
This study is interested in 16-19 year olds' experiences of caring for a parent with a chronic illness or disability. We are interested in ways in which you feel caring for your parent(s) has affected yourself and your family.

Who is carrying out the study?
Suzy Gray, a Trainee Clinical Psychologist at the University of Surrey is carrying out the study and is being supervised by Dr Sue Thorpe, Research Tutor.

What does taking part involve?
Taking part in the study will involve participating in an interview, which will last about one hour.

You don't need to prepare anything for the interview. We simply want to hear about your own personal experiences of being a young carer. We would like to ask you questions about what your experiences of caring have been and how they have affected you and your life.

We realise that these issues may be sensitive and if you don't want to take part you do not have to give a reason and you will not be asked about it again.

Similarly, if you decide now that you would like to be interviewed you are still free to withdraw at any time during the project without giving a reason if you change your mind. This will in no way affect the support you receive from the Young Carers project.

If you would like to take part, simply send back the completed slip and consent form and you will be contacted to arrange a suitable time and place for the interview. However if you decide not to take part you do not have to do anything - if we do not hear from you we will assume you do not wish to take part and will not contact you again.

Will what I say be confidential?
If you decide to take part, what you say in the interview will be completely confidential and anonymous.

We will audio-record and later transcribe the interviews, removing any identifying information. The results of the study will not be presented in any form that can reveal who you are.

Why is my reply important?
If we know more about how young carers experience changes in their lives as a result of caring for a parent we can think about ways to support them by building on their strengths. In this way the resources, capabilities and assets of young carers can be recognised and used to inform services.

After the study is completed we will ask if you would like a report to be sent to you to let you know what we found and how it will help us.

If you have any queries at all about this study, please contact
Suzy Gray,
Trainee Clinical Psychologist:
Address: PsychD Clinical Psychology, University of Surrey, Guildford, Surrey, GU2 7XH
Email: psmdsg@ surrey.ac.uk
# APPENDIX IV: CONSENT FORM

## CONSENT FORM

<table>
<thead>
<tr>
<th>Title of Project: Experiences of being a Young Carer.</th>
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<tr>
<td>Name of Researcher: Suzy Gray (Trainee Clinical Psychologist) Supervisor (Dr Sue Thorpe)</td>
</tr>
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</table>

Please initial box to indicate your agreement.

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. This will not affect medical care or legal rights.

3. I understand that the interview will be audio-recorded and transcribed verbatim and that the tapes and transcripts will be stored securely according to the Data Protection Act.

4. I agree to take part in the above study.

<table>
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DEMOGRAPHIC QUESTIONNAIRE

The following information is collected so that people who read the final report can know more about the people who have taken part in the study. However, none of this information will be used to identify you as this research is completely confidential.

1. How old are you? _____________________________________________

2. Are you male □ or female □ (tick appropriate box)

3. Which relative suffers from an illness/disability _______________________

4. How long have they been ill? _____________________________________

5. What is their illness/disability? ____________________________________

6. At what age did you start caring for them? _________________________

7. Please indicate which caring tasks you carry out (tick appropriate box(es)):
   □ Personal care
   □ Emotional support
   □ Household chores
   □ Looking after brothers or sisters
   □ Other caring tasks (please specify)____________________________

8. What is your current occupation?
   □ Student
   □ Employed part-time (please specify)______________________
   □ Employed full-time (please specify)______________________
   □ Unemployed

9. How would you describe your ethnicity?
   Chose one section from (a) to (e) and circle the appropriate response to indicate your cultural background

   White
   British
   Irish
   Any other White background, please write in below

   _____________________________________________________________
Mixed
White and Black Caribbean
White and Black African
White and Asian
Any other mixed background, please write in below

Asian or Asian British
Indian
Pakistani
Bangladeshi
Any other Asian background, please write in below

Black or Black British
Caribbean
African
Any other Black background, please write in below

Chinese or other ethnic group
Chinese
Any other, please write in below

Thank you for taking the time to provide this useful information.
APPENDIX VI: INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

PRELIMINARIES
- Thank the interviewee for agreeing to take part.
- Introduce myself and the nature/aims of the research topic.
- Confidentiality: all answers will be kept confidential, with any identifying features (such as your name) changed. This will ensure that you cannot be recognised from your answers when the study is written up as part of a doctorate qualification. The study may also be published in a professional journal and you will be asked if you would like a copy of a report of the findings. You and your answers will not be discussed with anyone other than my supervisors. Confidentiality will only be broken if there is a concern that you or someone you know is at risk of being harmed.
- Repeat request for consent to carry out and audio-tape interview
- Address any further questions the interviewee wants to ask.

INITIAL QUESTIONS
1. Why did you first start attending the Young Carers service?
2. Could you tell me a bit about who you help care for?
3. (If person became ill during child's lifetime) How have things been since your family member became ill?
4. What do you think and feel about your life now?

INTERMEDIATE QUESTIONS
5. Have you learned any lessons through caring for your family member?
   - How have you learned this?
6. Have any changes occurred in your life that you think are related to living with someone with a chronic illness?
   - (If changes reported) Have your thoughts and feelings about caring for your family member changed over the years?
7. (If positive changes reported) How do you think these changes came about?
8. Are these changes important to you?
9. Do you think this experience could affect your future?
10. Do you think this experience influences the way others see you?

ENDING QUESTIONS
11. With your experience in mind, what advice would you give to someone who had just found out their family member was ill?
12. Is there anything that you might not have thought about before that occurred to you during the interview?
13. Is there anything else you think I should know to help me understand your experiences better?
14. Is there anything you would like to ask me?
APPENDIX VII: EXAMPLE OF CODED TRANSCRIPT

Kwame (participant two) analysis

R: Ok, so I wondered if you could start by telling me a little bit about why you started attending the young carers project?

P2: Umm, yeah basically a couple of years ago when my mum had my sister, my only and younger sister I think there were some complications and basically um she had to stay in hospital longer than was due and I think she had an um she had a stroke. She did come close to death um and for the for the first year she wasn’t the same you could kind of see and I think she lost the vision in one eye

R: Right

P2: But to be honest things now are getting better. Things are a whole lot better yeah. That’s basically it yeah.

R: And how did you find the young carers project?

P2: Umm after, after that I think um I got a call and they said “we do outings” they told me like a bit about the organisation that they do outings and stuff. They seemed ok and I didn’t have to pay any money for the outings and stuff so it seemed ok. I met people who were like who have similar experiences with me and um yeah. So basically I got a phone call from them.

R: Right so they managed to contact you.

P2: Umm basically, I don’t know how they got my details. Probably through the hospital someway or something. Yeah.

R: So can you tell me a bit about who you help care for then?

P2: Umm with regards to my mum um at the start it was um more or less everything. It would be like changing my little sister, um doing the shopping, a lot of the cleaning, a lot of the household work.

R: Yeah.

P2: Umm but as obviously with education it’s getting more and more intense – I’m in my A2s now - I’m going to be at university next year. It has got less. My mum’s um ability and what she

Staying in hospital
Having a stroke
Coming close to death
Sensing difference
Losing abilities

Getting better
Noticing improvements

Hearing about YC service
Offering trips
Explaining organisation
Assessing YC service
Accessing free service
Meeting people with similar experiences
Hearing about YC service

Not knowing how they found details

Increasing educational demands
Increasing educational demands
Improving health

Increasing educational demands
Increasing educational demands
Improving health
can do has got better

R: Right?

P2: But it's actually it's kind of ironic cos err my dad actually suffered a heart attack three months ago.

R: Gosh

P2: Yeah I know I know it seems like I've been through a lot but no it's actually not that bad. Um yeah and that was kind of quite difficult to take it all in. Yeah. So I don't know whether you wanted to move onto that?

R: And how did you manage, and your family manage that? Did you find you had to take on more responsibilities again when your dad had his heart attack?

P2: Um cos I'm the oldest in the house I had to kind of take the man role, organising the household, the shopping, visiting him, making sure he's got his right materials and stuff and stuff like that so yeah. I didn't actually mention him in that [points to questionnaire] cos it was through my mum's illness that I met the young carers.

R: Yeah indeed. And how have things been since your mum had her stroke? How have things been for you?

P2: Umm. At first it was tough. I find myself, I found myself falling behind in my schoolwork a little bit. But like as I've said before she's a whole lot better now. She's a whole lot better. The vision in one of her eyes is still not completely there, so as a result she's labelled as disabled.

R: OK.

P2: Umm but yeah things are a whole lot better. I'm on top of my schoolwork, obviously university in September when it didn't seem like it was going to be that way at one point. So yeah things are going very well at the moment.

R: Can you tell me more about how things have moved from not seeming as though you might not get to uni to now being getting ready to go?

P2: Yeah umm. What was the question again sorry?

R: Umm how things have kind of moved from that stage of not feeling like you'd be able to go to now thinking about September?
P2: Umm it's a big relief. A huge a big weight off my shoulder. Before it seemed like my future was uncertain. I didn't know I didn't know where I was going but now with my mum getting better and that, the household becoming more organised and stuff like that I've got more sense of direction.

R: Ok.

P2: Definitely

R: So things feel as though they're a bit more stable now?

P2: More stable yeah.

R: And what are you going to go and study at uni?

P2: Information technology and management for business.

R: Right so a combination of both of your favourite A-Levels?

P2: Both of my favourite subjects yeah.

R: Ok and what do you, this is quite a general question, but what do you think and feel about your life as it is now?

P2: Sorry?

R: What do you think and feel about your life as it is now?

P2: Very relieved. Umm in a sense carefree cos my mum is a whole lot better now. Umm like I said before my life is a whole lot more organised now. It was a bit when my mum did fall ill - very hectic.

R: Yeah.

P2: I was very busy always off my feet and stuff so I feel more grounded now. Definitely.

R: Do you think you've done something to make your life more organised or has it happened that way?

P2: Yeah I haven't let um I've tried my best not to let the situations get the best of me. And I kind of see it as um [pause] If you do have a bad patch in your life that when you come out those kind of things will only make your stronger.

R: Yeah?
P2: And that's the way I've seen it so I haven't been "oh it's always going to be like this". After all I dunno so-to-speak famine there's always going to be a feast afterwards is the way I see it. So it didn't bother me too much.

R: How do you think you've got those ideas about "things will only make you stronger"?

P2: Umm through church. I attend church every Sunday. Umm I sing as well I sing at church and um yeah my faith is very strong and I think that's um due to that definitely.

R: Mmm. And do you think your faith has then helped you through kind of your mum being ill and through that process?

P2: Yeah definitely definitely.

R: In what way?

P2: Err [pause] That's a really good question.

R: A deep question!

P2: Umm yeah I dunno it's kind of like the way I see it obviously because I go to church I believe in God. I see that no no situation is too big for him, so what I do is I kind of I kind of I kind of let go of it and I just give it to him to sort it out for me. And once I let go of it and I stop thinking about stuff I see that it kind of sorts itself out for itself.

R: Right.

P2: That's the way I see it yeah. Is that enough explanation?

R: It is I think - let me check if I've got it right - it's kind of like putting your trust in

P2: In God

R: In that God will sort things out and make sure things will work out the way they're meant to be?

P2: That's exactly it. Yeah exactly that.

R: Right and have other members of your family found that their faith has helped them through?

P2: Yeah and their faith has strengthened as a result.

R: Would you say the same for yourself?

R: Um. Do you feel you’ve learned any lessons through caring for your mum?

P2: Um, I’ve learned the importance of caring and being while others may be suffering, like being resilient and being strong. I’ve learned how to do that. As a result I actually feel like I’m going to be a very good husband when I’m married [laughs] Not to be too cocky or anything! Um yeah I think that’s about it yeah.

R: Right and how do you think you’ve learned that lesson about being resilient and strong and the importance of caring?

P2: Through close family, close family. Not necessarily, not necessarily my dad cos my dad did suffer as well. He almost in a sense had a breakdown when my mum fell ill. But yeah umm family were constantly coming round, saying “she’s going to be fine”, cooking us food. Cos obviously my mum was the main, is the main cook of the house and when she was out for a little bit she couldn’t do that and um. So yeah, definitely close friends and family helped.

R: And have any changes happened in your life that you think are related to your mum being ill?

P2: Any changes in my life... At one at one point socially I wasn’t able to go out because I didn’t want to put my mum first. So that’s obviously a change with regards to my lifestyle. Um I think I’ve found that at the time I think I was in year seven or year eight at the time and my schoolwork did suffer a bit and I was it was quite bad because um obviously I’d just started secondary school and that’s the time when you need to kind of build the foundations to get you up to GCSE level and AS and A2. Yeah so definitely those two points there.

R: Ok, and how do you think you overcame those two points?

P2: Um through being obviously resilient and being diligent as well and being persistent, just mostly continuing not giving up. Just continuing to do what I do and trying to do it at a high level as well.

R: Ok, and it sounds as though you’ve succeeded in that.

P2: Yeah.
R: You're off to uni in September

P2: Yeah I had an interview with UCL.

R: Oh right?

P2: Which is one of the top five universities. So yeah. And I actually got a letter saying that I've got in.

R: Oh congratulations.

P2: Thank you very much. It's a conditional offer of course so I can't afford to let that I obviously still need to work hard to get the grades to get in.

R: That's brilliant news.

P2: Thank you very much. Thank you.

R: How... I suppose I'm wondering if the changes about being resilient and seeing yourself as someone who is very resilient if that's an important aspect of how you see yourself?

P2: Yeah yeah definitely. The way the way that life... no one no one stroll through life and everything is just it's like a walk in the park and it's rosy - you all have your trials. You all have your battles that you have to fight and obviously you've just got to try to be of the mentality that if you are struck down you will only rise up.

R: Right

P2: Definitely.

R: You mentioned your faith and your family as two key factors that played an important role in having that mentality. Are there any other things that you think are important in that mentality?

P2: Umm no I don't think so actually. That's about it yeah.

R: Ok and do you think that your experiences of your mum being ill and caring for her will affect your future?

P2: Definitely. I mean with regards to me learning how to look after someone and care for someone umm I think definitely I will be a I will be a good husband um I think I'll be a good father as well. I've kind of learned to become um kind of selfless and not be selfish.

R: Right.
P2: Kind of put others before me where it is necessary kind of thing.

R: Ok and do you think that's different to other people of your own age?

P2: Yeah definitely definitely I have been told that um I'm 19 and as a black male I'm very different to other 19-year-old black males that you see. I've been told on a regular basis that. I mean I guess I can kind of see it myself as well to be very honest. Yeah.

R: And do you think your experiences have affected your relationships as well? [pause] In terms of your family, your friends...

P2: With with my family we've got closer.

R: Right?

P2: I would say we've become more of a unit, whereas before we were all doing our own thing but now we've definitely become a unit. With my friends I don't know I dunno why but I mean with what happened to my mum I've become more a more upfront person.

R: Ok?

P2: I've no idea why that is but I do speak my mind.

R: Yeah.

P2: Definitely I do speak my mind.

R: Ok so you're not sure how that happened?

P2: I'm not sure how that happened, but it coincided with my mum's illness.

R: Right and do you think your experiences have affected the way other people see you?

P2: Yeah definitely, people have said they have seen a change in me. I'm more focussed.

R: Ok

P2: I have more motivation. I have um a sense of direction since that definitely.

R: Did you notice those changes yourself as well?

P2: Yeah yeah.
R: How do you think they came about?

P2: It's kind of like the theory that um my mum and dad have added value to me. So the way I see it is that I have to um when I graduate and get a very good job I take care of them. As a kind of reward for them taking care of me. So to speak.

R: Right, so kind of a reciprocal relationship?

P2: Yeah definitely definitely.

R: Right and do you think that would have been the same if your mum hadn't have had her stroke?

P2: Umm that's a very good question. I couldn't say. I couldn't say.

R: Because you've never known...

P2: I'd never know.

R: Ok and with your experiences in mind what advice would you give somebody else whose mum had just had a stroke?

P2: Erm mm, try not to let the situation get on you too much. Try and be strong for yourself but also for others. If people see that you are, like especially with your family, like say you have a younger brother or younger sister. If you're if it's affecting you negatively and they see that it's never going to be a good thing.

R: Right?

P2: So as hard as it is, try and be strong, erm try and be responsible try and try and I dunno take the situation by the scruff of the neck kind of thing. Try and do whatever is possible to you know help.

R: Right.

P2: Is that does that make sense?

R: It does yeah. So kind of taking responsibility back.

P2: Definitely

R: And almost "getting on with things" in a way?

P2: Getting on with things yeah.

R: And is there anything that you might not have thought about before that's occurred to you while we've been talking today?
P2: What that I should mention?

R: Yeah, that you’re kind of interested in that you’ve thought about.

P2: Umm no, no not really.

R: It sounds as though you’ve thought quite a lot about how the experience has affected you?

P2: Definitely, definitely cos just when it happened, how I’ve changed has coincided with what occurred with my mum. And erm yeah definitely.

R And is there anything else that you think I should know to help me understand your experiences better?

P2: Errmm, well yeah I’ve already mentioned that my dad had a heart attack um two or three months ago. Errmm it hasn’t affected me badly at all. But it’s kind of made me see how difficult life is. My dad came from Ghana twenty or so years ago, he’s worked his way up and he’s not done badly he’s got a mortgage, a beautiful wife, three beautiful children. But the company he works with it’s not, it’s not a good company so I’ve kind of learned that I’ve got the opportunity to go to university so I want to work hard to get a good job. So, cos basically if you have a heart attack and it’s near fatal, I don’t think it was near fatal but he should have more time off work but they’re refusing to give it to him.

R: Really?

P2: Yeah so basically he has to go back to work – working twelve hours, thirteen hours seven to eight O’clock. It’s really bad so um you know I have to apply myself to work hard so I’m not in that situation so if um, heaven forbid that anything does happen to me that my family is taken care of. If my dad is to stop working, the house would break down. Basically, because he’s the chief earner. So yeah, I think that’s an important thing to know.

R: Mmm.

P2: Yeah I think yeah. That’s all. Yeah that’s obviously quite a bombshell, quite important.

R: It is yeah. I wonder how your previous experiences affected the way you coped when you found out your dad had a heart attack as well?
P2: Yeah um. [pause] Obviously it did because I'd dealt with it before I kind of knew how to deal with this one. But it was very different because it was my mum but this time it was my dad and he's the main man of the house. You know what I'm saying? I'm always second-in-line.

R: Ok.

P2: I'm always second-in-line when it comes to controlling the house, so that was, it was very different but I kind of used the previous situation with my mum to come up with the situation with my dad basically. Yeah.

R: And how is your dad now?

P2: He's fine.

R: Good.

P2: He's very fine. He's doing his exercises and stuff but I mean he's not as um I know he's not as strong as he used to be. He comes home from work more tired now. Just goes straight to bed basically. So I'm hoping to graduate or strike it rich as soon as possible so I can take care of them. Seriously.

R: Right, And that sounds like such a strong conviction to have really – to care for them?

P2: That's the fruit of my drive. That aspect of my... that's what I'm aiming for – to take care of them. They've got a retirement pad out in Ghana so I'd love to be able to send them off so they wouldn't have to worry again and I'd take care of my little brother and my little sister, which can be done.

R: How old are your brother and sister?

P2: My brother's erm 16 and my sister's 6.

R: Ok.

P2: Yeah.

R: And is there anything that you want to ask me? Anything about the research?

P2: Err no. But I have to say the questions were very good.

R: Were they things you'd thought about before? It sounds as though you've got quite a clear picture....

P2: Yeah because with my mum it happened kind

Learning how to deal previously Drawing on previous experiences to cope
Having knowledge of how to manage/Being different Masculine role
Differences between parents Being second-in-line to 'man of house'
Masculine role Using responsibility for house
Being second-in-line Drawing on experience
Having previous situation
Drawing on experience

Dad recovering Wanting to take care of parents (financially)
Not being as strong
Going straight to bed
Feeling importance of earning
Wanting to take care of parents

Caring as fruit of drive
Aiming to look after parents
Caring as fruit of drive
Having retirement plans
Providing for parents
Removing worries
Taking care of siblings
Removing worries

Time reflecting on
of a while ago, I've had time to look back and reflect upon it. That's definitely helped as well cos I mean if it'd happened last year I'd still be a bit bemused by the whole situation, but because it happened a while back it's kind of like I've seen where it's changed me and like moulded me so to speak.

R: I can see that actually. That makes sense.
<table>
<thead>
<tr>
<th>Name</th>
<th>Statement</th>
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| Sally | • And um all the things that I've been through as well as like, as well as looking after my dad it's sort of inspired me to err be the bigger person to succeed at, even though I've been through all that I'm still going to get out of it I'm still going to do something with my life. Um so yeah it's just, if anything it encourages me to be better than my dad.  
  • If anything it's made me stronger.  
  • because I've gone through it so many times before that I already know that it's in my mind and it's part of my life. |
| Kwame | • I have been told that um I'm 19 and as a black male I'm very different to other 19-year-old black males that you see. I've been told on a regular basis that. I mean I guess I can kind of see it myself as well to be very honest  
  • cos just when it happened, how I've changed has coincided with what occurred with my mum.  
  • I've had time to look back and reflect upon it. That's definitely helped as well cos I mean if it'd happened last year I'd still be a bit you know bemused by the whole situation, but because it happened a while back it's kind of like I've seen where it's changed me and like moulded me so to speak. |
| Jenny | • make me sort of better person  
  • I think I've done really well to be honest. But I don't really see it as a challenge then if you know what I mean. It's just how things are. |
| Nina | • I used to find it quite difficult at first because I remember when my brother was first born when I used to go to parties and things it used to be family parties where the adults were with the adults and the kids with the kids. ... And I didn't really fit in.  
  • when I'm at school my school friends see me more for like who I am |
| Gemma |  
| Anthony | • I think probably like um I'm quite grumpy |
| Angel | • I love helping people. It's part of my everyday life. I could do it for a living, quite easily  
  • I feel good about myself because I know I'm helping and I'm doing something good. |
| Natalia | • And I believe that in some way it will make me a stronger person, somehow, some way.  
  • I think it already happened to like making me a stronger person  
  • I'm not that sort of person any more.  
  • It definitely made me a stronger person in a way that I can understand other people  
  • I think because people think the same way that they couldn't do it that they see me doing it I think they might think I'm a stronger person in some way. |
| Elizabeth | • I always used to go to a group when I was quite young, probably when I was about 7 just of brothers and sisters of people with disabilities and so I think a lot of people there identified you as "the sister of someone with __", but I don't really talk to anyone at all from there anymore, so. No I think now I'm just seen for me. I hope. |
| Ewan | • People see me as an all round better person. |
A number of different issues relating to a person's 'identity' or 'sense of self' emerged from participant's narratives.

My own understanding of the term 'identity' probably best fits within a social constructivist or post-modernist perspective, whereby 'identity' is seen as fluid and constantly shifting according to context and relationships (Gergen & Gergen, 1988). Postmodernists, such as Foucault *et al.* (1988) do not believe that identity is a 'real' entity located within people, but instead that 'identity' is a way of talking about the 'self', a discourse. According to Foucault 'identity' is communicated to others through interactions with them and is a shifting temporary construction. Furthermore, from a post-modernist perspective, language is viewed as both central and creative in the construction of self and identity (Crossley, 2000). This position is markedly different from a realist perspective, which sees the 'self' as an entity that is located within a person and can in some way be captured and described as an object.

I was particularly drawn to the way in which people described themselves as a "better person" (Jenny, Ewan) or a "stronger person" (Natalia) as a result of their experiences of family illness. This led me to the literature regarding chronic illness as a biographical disruption (displacement of the structures in daily life (Asbring, 2001)). A large body of research has identified that chronic illnesses have the potential to hold significance for an individual's identity, as the biographical disruption necessitates 'biographical work' regarding identity. Asbring (2001) states that this biographical work can include the discovery of lost, remaining and new aspects of identity and a partial identity-transformation (Berger & Luckman, 1979) based on the new situation. Is it possible that the biographical disruption faced by the young people I interviewed relates to the changed responsibilities they found themselves facing? I wondered if participants' descriptions of themselves as somehow 'different' from themselves prior to family illness represented a form of partial-identity transformation "how I've changed has coincided with what occurred with my mum." (Kwame).

There also seemed to be a sense amongst some people as their changed 'self' being noticeably different from their peers as a consequence of their experiences:
I have been told that um I’m 19 and as a black male I’m very different to other 19-year-old black males that you see. I’ve been told on a regular basis that. I mean I guess I can kind of see it myself as well to be very honest (Kwame)

I used to find it quite difficult at first because I remember when my brother was first born when I used to go to parties and things it used to be family parties where the adults were with the adults and the kids with the kids…. And I didn’t really fit in. (Nina)

I wonder if this sense of ‘self as different’ related to transcending the experience of family illness and viewing the partially-transformed identity in light of this?

There also seemed to be a desire for individuals to be seen “more for like who I am” (Nina), rather than as a ‘young carer’ or person affected by family illness. This seemed to contrast with the recognition of valued aspects of identity gained from caring experiences (e.g. being a stronger, caring person). I wonder if participants were referring to a desire to be seen to be shaped rather than defined by their experiences? Or even to be valued for their personal qualities rather than their behaviour (e.g. their caring nature rather than the caring tasks they perform)? It seems important to recognise again that individuals hold multiple self-narratives (Nochi, 2000) and perhaps it is the case that particular self-narratives are valued more in social contexts (such as ‘me for who I am’ with peers or ‘me for being different from my peers’ with researcher?).

Finally, there was a sense of the process of integrating a person’s experiences into their sense of ‘self’ or identity. For some people this appeared to be a social process, as Sally described talking to people about her experiences: because I’ve gone through it so many times before that I already know that it’s in my mind and it’s part of my life. (Sally). This could be seen to relate to a post-modernist understanding of identity as inextricably linked to social contexts and linguistic processes. However, it also relates to McLean’s (2005) view of identity as a life story, constructed to make sense of one’s past, present and anticipated future by making meaning of past experiences. Therefore through the construction of a narrative
about her caring experiences, which she shared with others, Sally engaged in a
meaning making process (narrative identity processing, (Pals, 2006)), whereby this
experience was incorporated into her life story and hence informed her identity
(Pals, 2005). This theory also suggests that development of life story and narrative
identity is an active lifelong process.