

The experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital.

An interpretative phenomenological analysis

Abstract

This study explores the lived experience of parents of male patients who have been detained under a hospital order with restrictions (section 37/41 Mental Health Act 1983), subsequently conditionally discharged into the community, and then recalled under the restriction order back to hospital. While much research has focused on the impact of having a relative with a diagnosis of mental illness, there has been a dearth of research into the impact of having a relative detained in a medium secure forensic unit. As yet, no research has been conducted into the experience of families where their relative has been discharged from a medium secure forensic unit, returning to the community after a long period of detention. Neither has there been any exploration into what parents experience if their son is subsequently recalled under the restriction order back to hospital. Interpretative phenomenological analysis was used as a way of exploring this experience for six parents of five sons who had been conditionally discharged and subsequently recalled to medium secure forensic psychiatry units in the South-East. The analysis yielded themes which related to the personal and emotional impact that parents experienced in terms of a cyclical pattern of hope when their son was discharged, followed by loss and fear, accompanied by a sense of powerlessness when his mental state deteriorated, and relief together with disappointment at recall. There was a reappraisal of the expectations they had of their son which enabled them to regain hope for him. A further theme of

responsibility highlighted the responsibility that parents assumed for their son, doing what they can for him whether he was in hospital or the community. Although they desired him to progress and be autonomous, parents recognised that their son may never be fully independent and may always require their support. They hoped that when he was conditionally discharged they would be able to share this responsibility with the supervising team. However, it seemed that when their son's mental state deteriorated, parents struggled to enlist the help of mental health services and were uncertain as to who held responsibility for him. Feeling isolated and unsupported at this time, they also felt blamed by services, reciprocating by blaming services. Not only unable to get what they perceived as an appropriate level of help for their son from services while he was conditionally discharged, parents described trying to access a system that seemed impenetrable, and responding only when 'something had happened'. When he was finally recalled, they experienced the system as having engulfed their son, and recognised how difficult it would be to get him out. Throughout the whole process they felt that their own expertise as parents was marginalised, and they described not feeling part of the team despite Governmental stress on carers being recognised as expert partners in care by services.

A number of limitations of the study are discussed, together with the researcher's reflexive account and implications for practice. The study offers a deeper understanding of what parents in this situation may experience, and offers a broader perspective for those who work with them.

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Contents of CD

For all participants:

Interview transcript

1st coding table of themes with referenced line number for quotes

1st coding themes with quotes

Themes by phase

2nd coding table of themes with referenced line number for quotes

2nd coding themes with quotes

2nd coding themes for conditional discharge and recall phases, with illustrative quotes

Glossary of abbreviations

CPA	Care Programme Approach.
CPN	Community psychiatric nurse
EE	Expressed Emotion
IPA	Interpretative Phenomenological Analysis
MHA	Mental Health Act 1983
MHRT	First Tier Mental Health Review Tribunal
MOJ	Ministry of Justice
NHS	National Health Service

1. Introduction

1.1 Aims and objectives

This study arose out of an interest which developed from my experience as a social worker while working with families of patients who had been detained in a medium secure psychiatric unit. In this role I listened to such families describe their (often difficult) experience of the events leading up to the admission of their son, and began to be aware of some of the challenges they faced.

The main objective of the study is to gain a better understanding of the subjective experience of people who have a son conditionally discharged from a medium secure forensic unit into the community, whose mental health then deteriorates such that he is recalled to hospital. It is hoped that this understanding will inform how professionals prepare and support parents prior to their son being conditionally discharged, and also prepare them for the possibility of recall.

The project is exploratory in nature in order to gain as rich an understanding as possible. Although a substantial amount of literature is available regarding the impact of mental illness on carers and other family members, there is little research into the impact of having a son detained in a forensic medium secure unit, and none into how families experience their son's conditional discharge back into the community, nor into their experience, concerns and dilemmas they face should their son again deteriorate and require recall to hospital.

1.2 Relevance of research to Counselling Psychology

This project aims to further understanding of the phenomenological experience of people who have a son conditionally discharged from a forensic medium secure psychiatric unit who then deteriorates such he requires recall to hospital. Counselling Psychologists seek to understand the perspective of their clients on an individualised basis. Research into the experience of such parents in this situation can only serve to enhance understanding.

Understanding what issues are relevant for people in this situation will enable professionals to work with them in a better informed empathic and respectful way in supporting them through what can be a traumatic and difficult process. The Mental Health National Service Framework (Department of Health, 1999b) emphasised the importance of addressing the needs of carers of people with severe mental illness by setting this as a key standard for health and social care services.

2. The legislative and statistical framework

This chapter outlines the legislative framework for the research. A brief explanation will be offered of the specific legislation pertaining to the study, and recent statistics which set the patient group relevant to this study within the wider mental health context. The Ministry of Justice (MOJ) oversee this group and have provided a rationale for provision of services.

“The Mental Health Act 1983 provides an alternative to prison and the criminal justice services for the management of mentally disordered offenders. It enables them to be detained in hospital for treatment and to be managed on the basis of their clinical condition and the risk they pose rather than any element of punishment. The rationale for the existence of the Secretary of State’s powers is that the control of patients who have been found to be dangerous and who are not being punished, should be vested in an authority which would have special regard to the protection of the public” (MOJ, 2010, p.160).

2.1 Hospital order with restrictions

If offenders are deemed to be in need of psychiatric treatment at the sentencing stage, they can be made subject to a Hospital Order under s. 37 of the Mental Health Act 1983 (MHA) which allows for them to receive treatment in hospital under Part III of the MHA (patients subject to criminal proceedings or under sentence). Offenders found by the court to pose a risk of serious harm to others can also be made subject

to a restriction order under s. 41 MHA. This additional order can only be imposed by the Crown Court and such restricted patients cannot be discharged, transferred from one hospital to another, or allowed leave in the community without the consent of the Secretary of State.

2.2 Conditional discharge

Patients detained under a hospital order with restrictions (referred to hereafter as s37/41) can be discharged either by a special First Tier Mental Health Review Tribunal (MHRT) where the presiding judge has experience of such cases, or by the Secretary of State. Discharge can be absolute, where there is no liability for recall to hospital; or conditional, where various conditions attached to the discharge are determined by the Tribunal or Secretary of State and the patient remains liable to recall to hospital under the original order.

2.3 Recall

Section 42(3) of the MHA provides that:

“The Secretary of State may at any time during the continuance in force of a restriction order in respect of a patient who has been conditionally discharged ... by warrant recall the patient to such hospital as may be specified in the warrant”.

The Mental Health Unit, part of the National Offender Management Service, takes this responsibility on behalf of the Secretary of State. For recall to be warranted there

must be evidence of mental disorder of a nature or degree warranting detention. The patient's mental health need not have deteriorated in order to justify recall; criteria for detention would be met because the nature of the disorder warrants detention in hospital and is necessary for the protection of other persons. If there is, or potentially is, deterioration, this is evidence that the disorder is of a degree that warrants detention in hospital.

The Mental Health Unit's policy is that patients will be recalled where it is necessary to protect the public from actual or potential risk posed by the patient *and* that risk is linked to the patient's mental disorder. Public safety will always be the most important factor. (Home Office, 2007).

2.4 Statistical analysis of the forensic population

In England, over 1.25 million people used NHS adult specialist mental health services according to the most recent statistics provided by the NHS information centre (NHSIC, 2011). Of these, 8.3% used inpatient services. Over 45% of admissions were compulsory detentions under the MHA. The proportion of people in hospital who are compulsorily detained has been increasing over recent years. More men are compulsorily detained than women (55% in NHS facilities). However the picture for those detained under Part III of the MHA (patients concerned in criminal proceedings or under sentence) is different; 78% detained patients are men. For restricted patients, this rises to 87% men (MoJ, 2010). Reflecting the pattern of compulsory detentions, the number of mentally disordered offenders detained as restricted patients in hospital has increased steadily since 1999, with 4,300 restricted

patients in 2009 (MoJ, 2010). Restricted patients have an older age profile than the general prison population with 4% less than 20 years; 89% aged between 21-59 years and 8% over the age of 60. The majority (48%) of these men are between the ages of 21-39.

There are no published statistics for conditionally discharged patients, but Shuttlewood from the Mental Health Casework Section at the Ministry of Justice has provided figures (personal communication, 7th March 2012) which indicate that currently the gender divide for conditionally discharged patients reflects that of the hospitalised restricted population, with 87% males, although they are slightly older than the hospitalised restricted population with the majority in the 30-49 age group. Recalls to hospital are also increasing annually, with 201 patients recalled in 2009, compared with 87 in 1999 (MOJ, 2010, p.160).

Although no statistics are available for relationship status in the restricted patient population, other studies indicate the prevalence of parents acting as carers over that provided by spouses or siblings (Ridley et al., 2010; Wane et al., 2009). For the purposes of this study, this profile of restricted patients provides a rationale for examining the experience of parents of sons who are subject to a restriction order under the MHA.

3. Literature review

3.1 Outline to the chapter

There is a substantial body of literature examining the impact of mental illness on the family. Much of this has been couched in terms of burden, with some emphasis on how this can be measured and with what factors these measures might be associated. Research has also investigated how carers and families cope with this stressful situation. It is recognised that the impact of mental illness on families can change over time with the course of the illness, for example at crisis points such as when the family member is hospitalised. Thus some studies have explored the impact of admission to hospital on families and carers, with a common theme of difficulties being exacerbated by the poor treatment families receive from professionals. It could be argued that any impact on families in having a family member with mental illness and detained in hospital is compounded by the addition of offending. Particularly in line with Governmental policies on carers, research has explored the needs of carers and families of patients within the forensic services and this will be discussed. The paucity of research into experiences of parents of such forensic patients serves to highlight that this is a neglected area that warrants attention. The introduction reviews relevant studies and argues for the importance of the current study.

3.2 The impact of mental illness on the family

Since the deinstitutionalisation from psychiatric hospitals in previous decades, family members have become the most important caregivers for adults with major psychiatric disorders (Cuijpers, 1999; Solomon & Draine, 1996). If caring for a person with severe mental illness challenges professionals, it is perhaps even more challenging for those such as parents who lack appropriate training and experience (Milliken & Rodney, 2003). The impact of providing care for a family member diagnosed with a mental illness has been extensively researched and found to be multidimensional (Schene et al., 1998; Szmukler et al., 1996). For example families have reported mental health problems and impaired relationships, which they attributed to caring for a mentally ill relative (Östman, 2004), financial burden (Johnson, 2000); and stigma (Corrigan et al., 2006; Corrigan & Miller, 2004; Phelan et al., 1998; Lefley, 1989). Feelings of fear, guilt, depression, powerlessness and anger are commonly reported (Askey et al., 2007; Milliken, 2001; Parker, 1993) as is worry about the future (Parabiaghi et al., 2007; Rose et al., 2006).

Grief and loss are experienced as parents respond to the changes in the child they once knew and for whom the anticipated future is lost (Penzo & Harvey, 2008; Goddres et al., 2005; Ozgul, 2004; Osborne & Coyle, 2002). An interesting aspect of loss co-existing with hope is highlighted in Bland and Darlington's (2002) study into hope as a perspective for family caregivers of people with serious mental illness. They noted the "close connection between hope for the future and loss in the present, whether this was of loss of what the ill person had once been, loss of their potential, or loss of the shared relationship" (p.63) and pointed out that "hope for

recovery in the future is held in opposition to the grief for what has been lost to the illness” (p.64). Although most researchers highlight the negative impact on families of having a mentally ill family member, positive aspects are also noted such as a satisfying relationship between the carer and the mentally ill relative (Bulger et al., 1993) and experiencing a feeling of pride in their relative’s courage in overcoming adversity (Pickett et al., 1997). This positive focus perhaps reflects the emergence of the recovery vision of mental illness on the family (Lefley, 1997).

Investigating what factors might be associated with psychological distress in relatives of people with chronic schizophrenia; Winefield and Harvey (1993) used a variety of standardised scales to measure the well-being of relatives which they associated with variables for both caregivers and the diagnosed family member such as age, gender and behavioural disturbance. They found that behavioural disturbance in the diagnosed family member contributed to caregiver distress.

3.3 Burden and measurement of burden

In an attempt to quantify the impact of caring for a family member with mental illness in order that this could be studied in relation to various aspects of the caregiving experience, efforts have been made both to define the concept and produce standardised measures. Families can feel overwhelmed by the effort that is needed to support individuals with serious mental illnesses (Drapalski et al., 2009). The degree of burden experienced as a result of stress is considered to be multidimensional, affecting the life of parents, the rest of the family, and their social network (Foldemo et al., 2005).

Researchers have distinguished between objective and subjective burden (Lefley, 1989). Objective burden is commonly accepted to refer to disruptions to the family unit such as changes in family roles and relationships, for example having to take on extra responsibilities; and financial hardship (Lelliott et al., 2003). Objective burden is often associated with loss of social support and a reduced participation in social activities (Rose et al., 2002). Subjective burden has been identified as the psychological impact of the illness on family members (Schene, 1990).

Researchers have developed a variety of instruments to measure burden. Earlier measures lacked agreement in the operational definitions of objective and subjective burden (see Schene, 1990, for a review of such instruments) but also failed to take account of the dynamic nature of the burden associated with having a family member with mental illness (Hatfield, 1997). Hatfield suggested that it would be more important to focus on how the needs of families change as their relative improves than on any increase or decrease in burden.

In an attempt to achieve a change sensitive measure, Schene and van Wijngaarden (1992, cited in Schene et al., 1998, p.610) developed the Involvement Evaluation questionnaire (IEQ)) which is a self-report questionnaire containing three sections relating to general information about the patient, caregiver and household characteristics, relationship between caregiver and patient, help seeking and coping; caregiving consequences; and an eight item distress scale of psychosomatic symptoms that are thought to occur among family members of psychiatric patients (Schene, 1990). Using this measure, Schene et al. (1998) found four domains in a

sample of mostly mothers with chronically ill sons; tension, supervision, worrying and urging. These domains were related to the patient's symptomatology, contact between the relative and the patient's mental health professional, and the contact time between the patient and their relative. Greater worrying was associated with less contact time with the patient; while the patient's current symptomatology was associated with caregiver distress. However they note that this measure does not take account of the relative's appraisal process.

Other researchers have used a variety of measures in order to investigate hypothesised associations between aspects of caring. For the most part these have involved questionnaires relating to the specific factor under investigation. For example, Pickett et al. (1997) explored the parental relationship with adult children with severe mental illness. They used a 16-item questionnaire to rate the quality of relationship, a 12-item scale to measure affective and cognitive burden, and a dichotomous measure of whether the child had a psychiatric diagnosis. Magliano et al. (2003) used five self-report questionnaires in their exploration of the effect of social network on burden in relatives of patients with schizophrenia. They found an association between a supportive social network and lower levels of burden. In a study relating burden with coping style, Budd et al. (1998) developed their own questionnaire to measure coping style which they related to scores on three other instruments; measuring cost of care, general health, and the carer's rating of their perception of behavioural disturbance in their mentally ill relative. They found that burden was related to coping styles. Collusion, criticism, coercion, overprotectiveness, emotional over-involvement, and resignation were all associated with higher levels of carer burden. Foldemo et al. (2005) investigated the association

between quality of life and burden in parents of outpatients with schizophrenia using a 68-item questionnaire to measure quality of life and a 19-item Burden Assessment Scale as developed by Reinhard et al. (1994). Burden on this scale is rated as 'a lot, some, a little, and not at all'.

Objective measures are limited when used to quantify subjective experience, and they cannot measure the lived experience, both complex and unique to the individual. Items on checklists can be ambiguous and yield only thin descriptions of complex situations. Offering the respondent dichotomous choices cannot adequately capture the patterns in the particulars of peoples' lives. As Coyne and Downey have commented (1991, p.420)

"The limitations of such instruments may be fundamental, and their objectivity illusory, particularly when it comes to substantive interpretation of their correlates....the validity of [qualitative] data will undoubtedly exceed that of investigators' blind inferences about what circumstances led a respondent to endorse an item on a checklist".

Subjective burden is just that, a subjective experience rather than a discrete, universally defined concept. Thus the difficulty with measuring 'burden' is that the measuring instruments will necessarily focus on specific aspects of that experience according to the specific interest of the researcher. While this may be useful in terms of exploring the associations between narrowly defined factors, the process can ignore other potentially crucial aspects. Participants are forced into choosing between or responding to categories that may not reflect the subtleties of their experience. Subjective measures lend themselves to exploration through a

qualitative methodology which allows for the richness of the individual's experience to be expressed. Wynaden et al. (2006) have noted that to date most research on caring has focused on measuring burden and not the experience from the carer's perspective. Thus their experience remains largely hidden.

3.4 How families cope with this impact

If carers and families, and more specifically parents, are faced with managing the impact of having a relative with mental illness, the strategies they use to handle this situation are often labelled as coping styles (Östman & Hansson, 2001). The recognition that operationalising the notion of burden remains problematic, led to Szmukler et al. (1996) investigating caregiving within a stress-coping framework; a stress-appraisal model which had originally been proposed by Lazarus and Folkman, (1984, cited in Szmukler et al., 1996, p.138). According to an appraisal model, objective facts are given meaning by the personal interpretations assigned to them. Szmukler et al. (1996) noted difficulties in the whole concept of burden, pointing out that objective burden, which is supposed to relate to disruption in the caregiver's life, may be erroneously ascribed to their relative's illness, and that disruption may have occurred through other life events. Furthermore they suggest that researchers have rated subjective burden as attached to elements of 'objective' burden. They point out that if an aspect of caregiving is not included in the list of objective burdens, it will consequently be excluded from being measured as a subjective burden. This can lead to excluding distress arising from 'non-objective' aspects of caregiving such as grief over the loss of the person the patient was or could have become. They conceptualised the caregiving experience as an appraisal of its demands. Thus they

viewed the patient's illness, behaviours and disruptions to the carer's life as the stressors appraised by the carer. Mediating factors in the appraisal included the level of social support and the quality of family relationships. The interaction between the appraisal and the carer's coping strategies, or efforts to control the stressor demands, result in outcomes in terms of physical or psychological well-being or morbidity. Based on this model, they developed a self-report inventory around the experience of caregiving and found that well-being was associated with positive appraisal and less use of emotional coping strategies such as blaming, criticism and displacement of anger. They suggested that emotional coping follows failed efforts at practical coping. Östman and Hansson (2001) have suggested that relatives use problem solving coping strategies when they are in situations amenable to change; whereas emotion coping strategies are used in situations that are chronic and unchangeable.

Hatfield (1997) agrees that coping is directly influenced by the way the family member chooses to view the situation. She points out that families may have much more control over how they perceive, think and feel about things than they do over their relative's behaviour. Barrowclough et al. (1996) found that cognitive appraisals of the illness are related to caregiver distress; while Pickett et al. (1997) found that parental caregiving burden was related to parents' appraisals of their relationship with their adult child, with lower levels of burden indicative of more positive appraisals.

Extending the idea that appraisals and coping and perceptions of the illness could be interlinked, Fortune et al. (2005) used a number of standardised quantitative

measures to examine whether coping and appraisals were important in accounting for variance in psychological distress in relatives of patients with schizophrenia, or whether this could be determined by their perception of the illness (psychosis) alone. A list of 49 problem behaviours were generated, and participants asked to rate how much the problem bothered them (threat) and how well they felt able to cope with the behaviour (control). Responses were dichotomised and positive responses summed to give threat and control appraisal variables. Coping was quantified by respondents indicating the extent they used the 14 coping strategies listed in the Brief COPE (Carver, 1997) from 1 (I don't usually do this at all) to 4 (I usually do this a lot). The authors found that coping through seeking emotional support, the use of religion / spirituality, acceptance, and positive reframing were all associated with less distress. Higher threat and weaker control appraisals were also indicative of higher distress.

Although the above studies have been helpful in separating out the strands of coping, appraisal and distress, to date this has not been explored using a qualitative approach. These concepts are broad and there may be wide variation in meaning between the participants. A qualitative study, particularly using a phenomenological methodology would be able to explore this meaning in depth, thereby enriching our understanding of how relatives both appraise and cope with their situation.

More recently, Wrosch et al. (2011) have applied the findings of research into goal adjustment capacities to people caring for family members with mental illness. They suggested that caring for a family member with mental illness can represent a chronic stressor that renders the carer's own desired goals as unattainable. They found that both the capacity to abandon goals seen as unattainable and to re-

engage with new goals, were significantly associated with how they cope with the stressful situation of caring for a family member with mental illness. Those able to disengage blamed themselves less frequently for problems associated with caregiving, and used substances to regulate their emotions less frequently than those who found disengagement more difficult. In addition they experienced less caregiver burden and a higher level of subjective well-being. Although this study related to the carer's goals, it could be hypothesised that the capacity to adjust goals according to whether or not they are attainable may also influence the carer's capacity to adjust their hopes and expectations for others, specifically the ill family member.

3.5 The impact of mental illness on the family over time

Hatfield (1997) has pointed out that more research is needed into life cycle issues in mental illness and caregiving, as neither the family member nor the caregiver remains in stasis over time. Muhlbauer (2002) used a qualitative methodology to examine this experience in American families and found that families typically experienced six phases: development of awareness, crisis, instability and recurrent crises, movement toward stability, continuum of stability, and growth and advocacy. He suggested that needs characteristic of each phase were evident, and that further research should investigate whether his findings are consistent in other groups.

Expressed emotion (EE), "hostility, criticism, and emotional over-involvement directed from other people toward the patient, usually within a family" (Kring et al., 2010, p.G4) has been shown to be associated with relapse (Breitborde et al., 2009).

A full examination of expressed emotion is beyond the scope of this review. However, in a review of the literature on EE, Heru (2000) proposed that parental EE may be a transactional process that may originate in the patient's disruptive behaviour and is part of the adaptation to chronic illness. She suggested that if this adaptation is problematic, then EE will be high and predictive of relapse. Furthermore, her argument is used to support the finding of Stirling et al. (1993) that emotional over-involvement at the start of the illness can develop into criticism of the patient in later stages. Heru (2000) recommended that longitudinal studies investigate the family's response to mental illness as she suggested that this may occur in recognised stages, "although the process of adaptation may vary from family to family" (p.101). Recognition of this response as potentially individualised with some commonality supports an idiographic qualitative methodology and supports the notion that the experience of having an adult child with mental illness can change over time.

Milliken and Rodney (2003) found that parents caring for a child with schizophrenia periodically revise their parental role and identity in response to their child's illness trajectory. Their grounded theory analysis of parental interviews conducted in British Columbia revealed that parents assumed responsibility for protecting, nurturing and directing his or her care. However, this role was often limited by the legal system, mental health professionals, and their adult child, because of the societal designation of their child as a self-determining adult. Perceiving themselves as disenfranchised, parents felt they had lost their right to care for their child whom they saw as unable to care for themselves adequately. Their study highlighted the dilemmas that parents

can face at different stages of their child's illness which can add to the powerlessness and moral distress they experience.

Family burden for relatives of patients with mental illness appears to remain stable over time (Chadda et al., 2007; Magliano et al., 2000) although burden decreased in families who adopted less emotion focused coping strategies, received practical support from their social network, and when the patient's social functioning improved (Parabiaghi et al., 2007; Magliano et al., 2000).

Investigating the course of grief of parents whose children suffer from mental illness, Goddres et al. (2005) found a reduction in grief, but only after an extended period. They suggest that parental grief may change across the life course of the illness, "possibly reflecting different challenges, issues and impacts of the illness" (p.92). In a qualitative study of families, primarily parents, of 180 people with serious mental illness in the US, Johnson (2000) found that the ways in which families deal with the process of the illness varied significantly at different stages of the illness.

The different challenges that families face affect what they need at these times. Drapalski et al. (2009) note that the need for information, guidance and support does not dissipate over time, but rather changes in the content, focus and intensity of what services are best able to address those needs. A confirmatory survey conducted by Lakeman (2008) found that families perceived their needs in relation to acute and community care differently.

3.6 Impact of detention

One challenge that disrupts the routine of caring for a family member with mental illness is when the person is hospitalised. Phelan et al. (1998) found that many family members reported concealing the first hospitalisation of their relative to some extent, particularly if their relative did not live with them, was female, and had less severe positive symptoms.

In a qualitative study in the USA, Hanson, (1993) noted four distinct stages for families, the majority of participants being parents, in their process of dealing with a severe mental illness in a family member; prior to professional help, hospitalisation, community care, and return to care by the family. Although hope and relief were associated with hospitalisation, families also experienced role conflict and ambiguity during these transition periods. The study highlighted the exclusion that families feel by services when their relative is admitted.

If the experience of having a relative with mental illness is affected when the family member is admitted to hospital, is there any difference when they are re-admitted? Östman (2004) explored differences in burden between relatives of patients admitted for the first time and re-admitted patients in a Swedish multi-centre study. She used a semi-structured interview with 95 items developed from clinical experience, including dimensions of burden, participation in care, and attitudes towards mental health care in hospital. Respondents gave yes or no answers to facilitate a quantitative analysis. Generally there were no differences between the two groups. However relatives of patients admitted for the first time more often viewed the

psychiatric services to be of good quality and also more often initiated the admission to hospital. Östman suggested that these aspects may reflect families' hope of recovery for the ill person; "they may still expect great things from the psychiatric services" (p.612).

3.7 The poor treatment of carers and families by professionals

Added to the difficulties they face in having a family member with mental illness, families also describe having problems with services (Szmukler et al., 1996; Hanson, 1993). In a systemic review of the literature, Fadden et al. (1987) noted that despite receiving very little support from the professionals treating the patient, relatives rarely complain. More recently Johnson (2000) coded responses from a semi-structured interview of families exploring, amongst other aspects, their sense of competence in dealing with the mental health system. He found that families frequently reported feeling disregarded or dismissed as irrelevant by mental health professionals. Their opinion or knowledge was rarely sought, and they did not perceive themselves as being part of the team, even though they were expected to provide care for the patient post-discharge. He also found that although families recognised early warning signs of deterioration, this information was rarely heeded by mental health professionals. A phenomenological study conducted by Wilkinson and McAndrew (2008) aimed to understand the experience of family members when their relative was admitted to an acute psychiatric ward. Their methodology was specifically chosen in order that the researchers would be able to gain insight into the family members' subjective experiences and interpretations of their level of perceived involvement within this particular environment. Their study highlighted the exclusion

that families feel from inpatient services, leaving them feeling powerlessness and isolated. More recently, Small et al. (2010) have also used a qualitative methodology to focus on individual discourse as a way of understanding how family members experience health and social care professionals. Using information obtained from diaries completed by families over three months, together with semi-structured interview data, the authors noted the inadequate support families receive from mental health professionals and the conflict arising from families and professionals holding differing views, which in turn added to the burden of caring. Recognising the limited support available from standard mental health services, a study using Interpretative Phenomenological Analysis (Wane et al., 2009) investigated the impact of an assertive outreach team on couples caring for adult children with psychosis. They found that involvement with an assertive outreach team led to families feeling reassured and reduced their experience of exclusion. Similarly, using a family burden questionnaire and the Global Assessment of Functioning scale with over 500 families, Chen and Greenberg (2004) found that formal support from mental health professionals through information sharing and collaborative interactions with family members was significantly associated with a positive experience of caregiving.

3.8 The impact of mental illness and forensic involvement

If the impact of having a family member with mental illness is strong, this can only be compounded by the family member committing an offence that leads to their detention in forensic services (Tsang et al., 2002). Perhaps reflecting the specialist nature of forensic services, there has been relatively little research into families and

carers of patients in these services (MacInnes & Watson, 2002; Estroff et al., 1994) and what particular stressors they may face.

In recognition that carers need support to enable them to carry out their caring role, the Government has increased its spotlight on carers in terms of policy and guidance (Department of Health, 2010, 2008a, 2008b, 2002, 1999a). Guidelines for best practice in medium secure services (Health Offender partnerships, 2007) stated that carers should be involved in the care process as much as possible. Researchers have reflected this focus in terms of investigating what carers and families need. In an attempt to understand the needs of relatives of patients in a high security hospital, McCann et al. (1996) used a structured questionnaire, together with an analysis of minutes of a relatives' support group, to explore the stress felt by relatives in maintaining contact with the detained patient. Noting that the data provided an illuminating insight into the thoughts and feelings of relatives, the authors found that relatives felt they were not being supported, or allowed to contribute to the care of their family member. This finding is supported by MacInnes et al. (2010) who used a mixed methodology, asking carers of patients detained in medium security to rate their experiences with services on a 5-point scale, followed by an opportunity for them to expand on their answers. Their interview schedule was developed following consultation between the researchers and carer advisory groups. Carers expressed frustration at their lack of involvement while the most important support need that they highlighted was to be provided with regular and appropriate information.

A recent cross-sectional questionnaire survey into the provision of carers' support in medium and high secure services in England and Wales (Canning et al., 2009) found

that although most units provided some form of support there was variation in both type and level of support offered. The questionnaire included both structured and semi-structured items, with a statistical analysis of closed questions, and a thematic analysis of open ended questions. Services identified benefits of offering such support in terms of improved relationships and communication between staff and carers. Professionals in these services identified factors which they believed may interfere with the provision of support such as carers' previous negative experiences with mental health services. Although it is helpful to gain an understanding of what healthcare professionals perceive as problematic in terms of supporting carers, this study does not purport to offer insight into how the carers themselves may think and feel about this situation. A subsequent postal survey of services provided by medium and low secure services (Cormac et al., 2010) found that many services provide a poor service for carers, some not even complying with current legislation for carers.

Some researchers have explored the use of interventions that might assist families such as relatives support groups (McCann, 1993) and family therapy (Geelan & Nickford, 1999). Geelan and Nickford noted that within medium secure services few staff were trained in this type of intervention. The professional staff from the services who completed the survey questionnaire believed that the geographical distance between families and the unit hindered the provision of the family therapy. However, Absolom et al. (2010) found that 72% patients (across the range of secure services; low, medium and high) had regular contact with their relatives, not the poor engagement as previously identified as a barrier to the implementation of family involvement. Their analysis was based on the results obtained from structured questionnaires completed by clinical staff. The authors suggest that family

interventions may be complicated because of relatives' feelings such as "anxiety, hostility, stigma, shame or guilt arising as a consequence of the forensic and mental health issues faced by the patient" (p.360). A qualitative methodology would be ideally placed to explore what relatives actually do feel. A phenomenological approach would offer insight into their lived experience.

MacInnes and Watson (2002) used in depth interviews to examine the differences between forensic and non-forensic caregivers of individuals with schizophrenia who had recently been admitted to hospital; either to a regional secure unit or an acute admission ward. Using 14 categories of burden dimensions which had been developed from a previous study (MacInnes, 1998) the authors rated statements given by respondents during interviews according to these categories. They found that forensic caregivers were more likely than non-forensic caregivers to describe burdens relating to violence, and also 'annoyance' towards services. The latter related to caregivers' anger and frustration towards services when caregivers perceived indifference, and sometimes outright hostility to their concerns. Caregivers described not being allowed to take part in discussions relating to the care and aftercare of their relative, and denied information that could directly affect them or their family because of issues of confidentiality. They felt excluded from the in-patient caregiving process and about any developments, both positive and negative relating to the patient.

Specifically looking at the experiences of parents with a son or daughter suffering from schizophrenia in a secure forensic setting in the UK, Ferriter and Huband (2003) interviewed parents of 22 patients to explore the emotional burden they

experienced and their perception of the helpfulness of others in coping with that burden. They asked parents to recall experiences over a number of years rather than concentrate on current experiences that might overemphasise the burden of recent crises. The study was limited by the exclusion of participants from ethnic minority groups because of potentially confounding factors such as cultural variation as to perception of mental illness, and the experience of racism in the aetiology of mental illness. Experience of their child's illness was measured by a degree of burden scale, endorsement of items from a list of behavioural problems, and a focused life story interview which they had developed for a previous study. That the respondents raised additional difficulties to offered choices indicates the limitations of using such discrete measures. Interview data was examined for emotional content relating to parents' responses to the behaviour of others in the context of their child's disorder. Emotional themes were quantified, with references to stress found in all interviews, although this was not explored in detail. Other themes included loss of what might have been (91% respondents); fear (77%); grief (73%); and confusion (50%). The authors concluded that serious offending by their child had contributed to the stress felt by parents. Clearly further research is needed in terms of exploring the nature and quality of such experience, to offer a clearer and richer understanding. A qualitative phenomenological focus would helpfully provide further depth.

Noting the double burden carried by relatives of individuals who are both diagnosed as having schizophrenia and who show violent behaviour, Nordström et al. (2006) interviewed 14 parents of 11 adult sons, diagnosed with schizophrenia and referred for forensic psychiatric treatment in Sweden due to a violent crime. Their aim was to explore parents' experiences and emotional reactions. The patient chose which

parent should be approached and three couples were interviewed together. No comment was made regarding whether interviewing couples offered a different perspective from interviews with individuals. Swedish legislation allows for diversion to forensic psychiatric treatment if the crime is committed under the influence of a severe mental disorder. Using a grounded theory approach, their analysis showed four events as crucial and common to all parents; the onset of mental disorder, the diagnosis of schizophrenia, the violent behaviour or criminality, and the referral to forensic treatment. Each event evoked strong emotional reactions. Onset of mental disorder was characterised by guilt, helplessness and anxiety, and fear of what was happening. Some mothers felt that they were not respected but viewed as 'hysterical'. The diagnosis led to grief for the loss of their son's future. Parents expressed disappointment regarding earlier psychiatric care, and blamed psychiatric services for not having prevented the violence. It was important to them that their son was not regarded as a 'criminal' but as an individual with a mental disorder. Being referred for forensic treatment was associated with relief that they could transfer their responsibility to the psychiatric unit, and hope that he would now improve and have a future.

3.9 Overall summary and rationale for the present study

This review has highlighted the impact of having a family member with mental illness on carers and families. Researchers have attempted to measure this impact in terms of burden, by developing a variety of scales in an endeavour to quantify this phenomenon, while also appreciating its subjective nature. Such positivist approaches do not allow for an in-depth exploration of the experience of having a

family member with mental illness or acknowledge the complexities of this phenomenon for the individual. The majority of research has focused on families in the role of being a carer, particularly in the recognition that it is most often the family, and in particular parents, who take on this role for the severely mentally ill. Research has correspondingly investigated the needs of carers and families. However the experience of having a family member with mental illness cannot be reduced to the notion of being a carer neither can such experience be objectified in terms of definition and meanings as prescribed by the scientific community. A qualitative phenomenological framework would be most appropriate to explore this experience. A small number of studies have used qualitative methodologies for example in exploring the dynamic experience of having a relative with mental illness over time (Milliken & Rodney, 2003; Muhlbauer, 2002; Johnson, 2000) or when their relative is admitted to an acute admission ward (Wilkinson & McAndrew, 2008). Others have used similar approaches when investigating how people experience the mental health system (Small et al., 2010; Wane et al., 2009).

Studies into the experience of having a relative detained in forensic services are scarce. These have largely used survey approaches, or interview data which is then quantified in terms of pre-determined categories. Other studies have obtained data from healthcare professionals rather than from families themselves. The qualitative study by Nordström et al. (2006) reflects studies in the non-forensic population, exploring the experience of parents over the life-course rather than perceiving the experience as a static phenomenon. Their study reflects the experience of parents up until their son's referral for forensic treatment. However there has been no research to date investigating the experience of parents of patients who have

undergone an extensive treatment programme in medium security and who have been conditionally discharged back into the community. It could be hypothesised that conditional discharge is the culmination of hope for the future as expressed by parents in the Nordström et al. (2006) study. Treatment in medium secure services, especially for restricted patients, is lengthy, and such patients are not discharged until they are deemed safe enough to be returned to a community setting. Although many conditionally discharged patients are not recalled to hospital, a substantial number are recalled. Furthermore no research has been conducted into the experience of parents of sons who have been deemed well and safe enough to be conditionally discharged back into the community, but who then subsequently require recall. The lived experience of these parents can be illuminated using a qualitative and phenomenological methodology. A better understanding of this experience would assist health and social care professionals in their ability to empathise with parents in this situation. If parents feel understood, this in turn may improve relationships between them and mental health professionals. Finally it is hoped that such understanding would aid in the development of services for this group.

3.10 Aims and objectives

This study is concerned with the experience of having a son who is detained in forensic medium secure services under s37/41, conditionally discharged into the community, and then recalled to hospital. The study aims to:

Explore the lived experience of parents in this situation from a phenomenological perspective in order to have a better understanding of their experience.

4. Method

This chapter contains four sections. The first outlines my ontological and epistemological perspective. The second section offers a rationale for using Interpretative Phenomenological Analysis methodology as a framework for the study. The third section gives a detailed account of the design and procedures employed to analyse the data. The final section discusses limitations of the research..

4.1 Ontological and epistemological perspective

There is an ongoing debate as to whether the world has a real existence outside of human experience. Several different perspectives can be identified; these will be briefly outlined. Modernists view the world as real, and having essential properties that can be discovered by objective observation. A positivist epistemology aims to apprehend these properties. The researcher is assumed to be independent of the objective reality under investigation. Critical realists agree that there is an external reality, but acknowledge that this reality cannot be completely grasped or apprehended by humans. In contrast, postmodernism proposes a relativistic ontology that asserts that meanings are created rather than waiting to be discovered (Leary, 1994), and that “what once before had been construed as reality was now considered a negotiated experience” (Dickerson, 2010, p.354). The issue then arises as to whether constructions of reality are individual or a group phenomenon. Critical theorists suggest that realities are constructed through language by groups of people. Shaped through factors such as gender, politics and culture, ‘reality’

becomes objectified and assumed to be unchanging. The aim of critical theory research is to deconstruct these assumed realities in order that they can be examined and challenged. Critical theory research offers the opportunity for change by exposing the dominant, often powerful and oppressive discourses that serve to constrain and exploit. Researcher values are therefore central (Ponterotto, 2005). Language from this perspective is not seen as a window to experience, as in phenomenology which will be discussed below, but rather in terms of function; discourse as action.

An alternative assumption held by constructivists is that it is the individual who creates reality, rather than social groups (Hansen, 2004). Reality from this ontological stance is not unitary or objective, but different for each individual, dependent on the meaning that each individual attaches to their experience. According to Ponterotto and Greiger (2007), this ontology holds that there are multiple, equally valid realities which are apprehendable through many “intangible mental constructions, socially and experientially based, local and specific in nature, although elements are often shared among many individuals” (Guba & Lincoln, 1994, p.110). Phenomenology subscribes to a critical realist position, arguing that there is a real world independent of language. However what is experienced is a “phenomenal rather than a direct reality” (Eatough & Smith, 2008 p.181). As individuals define the world according to their own interpretation, the world and the person cannot be separated, as what is, is their experience of the world. This relative view is consistent with the critical realist philosophical position in that although there is a reality independent of the individual, the meaning of that reality is dependant on

them. Thus individuals experience reality differently by the meanings they attach to it (Larkin et al, 2006).

Husserl (1936, cited in Langdrige, 2008, p.1128) described a transcendental phenomenology, which aimed to accurately describe an individual's experience by focussing on the perception of the "things in their appearing" (ibid, p.1127). He viewed consciousness as intentional in that there is always an object of consciousness. Phenomenology from this perspective is interested in the relationship between a person's consciousness and the world. The world is therefore as experienced rather than as a separate entity. The only way of knowing how people experience their lifeworld is through their communication of that experience. The researcher is assumed to interpret the world through their own lens, and so can only apprehend the participant's world imperfectly. Husserl's model requires researchers to bracket their assumptions about the world in order to separate their experience from that of the participant. In contrast Heidegger (1962, cited in Larkin et al., 2006, p.105) acknowledged that as we use our own experience to interpret the experience of others we can never remain detached. This therefore entails a reflexive approach, where the researcher is mindful of their own assumptions about the phenomenon under investigation and is therefore better able to set aside their own understanding in order to attempt to see the view of the participant. Ricoeur (as cited in Langdrige, 2008, p.1136) has distinguished between interpretation or the hermeneutics of empathy, which seeks to understand the participants' world, and the hermeneutics of suspicion which engages in a much deeper interpretation. An interest in experience suggests a hermeneutic of empathy methodology such as Interpretative Phenomenological Analysis (IPA) (Smith, 1996). My own ontological

and epistemological stance is phenomenological within a critical realist paradigm. The research question assumes an interest in the experience of a specific phenomenon. My assumption was that I would be able to access, albeit in a limited way, the experience of each individual through their words which describe their thoughts and feelings, and that the phenomenological paradigm is best suited to answering the research question. Although the reality is that their sons have been conditionally discharged and recalled to hospital, my assumption was that each individual parent would experience this in a unique way.

4.2 Design

4.2.1 Choice of methodology: Interpretative Phenomenological Analysis

The methodology that would seem to fit best with my ontological and epistemological position and the research question is Interpretive Phenomenological Analysis (IPA) as developed by Smith (Smith & Osborn 2008). IPA acknowledges the individual experience of a phenomenon, and thus uses an idiographic approach.

IPA is theoretically based on symbolic interactionism (Mead, 1934, cited in Eatough & Smith, 2008, p.184) and critical realism (Bhaskar, 1978). Symbolic interactionism views humans as constructing their social world “through their intersubjective interpretative activity” (Eatough & Smith, 2008, p.184). Fade (2004) suggests that these different meanings can be identified through the speech and behaviour that individuals express.

IPA is comprised of two components, interpretation as the “I” component, and phenomenology as the “P” component. Phenomenology gives primacy to the lived experience and is concerned with the meanings that people give their experience. Through focusing on this lived experience of reality, the phenomenological approach (the “P” in IPA) enables an observer to understand how the phenomenon is experienced by the individual through the language that individual uses to describe their experience (Holloway & Todres, 2003). As already discussed, phenomenology is based on an assumption that empirical science is limited in its ability to yield a rich understanding of the world and thus highlighted the importance of the lived experience (Smith & Osborn, 2008). From this view

“it attempts to explore personal experience and is concerned with an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself” (Smith & Osborn, 2008, p.53).

The interpretative element of IPA (the “I”) acknowledges that the researcher takes on an active role in the dynamic process of research. The researcher attempts to gain an ‘insider’s perspective’ and thus achieve an understanding of the individual world of the participant, although this cannot be wholly or directly achieved. The researcher has their own assumptions and beliefs which influence their understanding of the participant’s world. From this perspective, the researcher needs to acknowledge their role within the research process by taking a reflective position, understanding that their own participation in the process influences the relationship and what might be expressed. As Smith and Osborn (2008, p.53) have noted, there are two aspects of interpretation entailed within this dynamic relationship in which

“the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world”. IPA draws on both the hermeneutics of empathy and the hermeneutics of suspicion. The researcher attempts to understand the participant’s world (hermeneutics of empathy) while also questioning “Is something leaking out here that wasn’t intended?” (Smith & Osborn, 2008, p.51). The “I” is where an “outsider” perspective (perhaps theory-informed) is added to the “P”. Smith and Osborn (2008) suggest that the hermeneutics of empathy and of suspicion are both important within a qualitative investigation, but recognise that the research question will determine the level of focus on each interpretative style.

This study employed a qualitative design conducted within the framework of IPA and concerned with the experience of having a son conditionally discharged and then recalled to hospital under s37/41.

4.2.2 Participants

4.2.2.1. Sampling in IPA

Sampling was necessarily purposive in order to illuminate the research question. IPA prioritises depth of analysis over breadth of sample, and most IPA studies have sample sizes in the range of 4-10 interviewees (Smith & Osborne, 2008). Six participants were interviewed to allow for a deep analysis of each participant’s responses and subsequently across the whole sample.

4.2.2.2. Inclusion criteria

The criteria for inclusion were that the participants were parents of a patient who had been conditionally discharged and subsequently recalled to hospital under s37/41; had remained in contact with their son during the conditional discharge and recall phases; and nominated by him as a potential participant. The parent-child relationship is different from other types of close relationships such as siblings or spouses and the majority of patients in medium secure psychiatric hospitals have either never married or have had a relationship breakdown either prior to or during their admission (MacInnes, 2010; Johnson, 2000). Limiting the study to the experience of parents increased the homogeneity of the sample.

4.2.2.3. Recruitment

Participants were obtained via a lengthy process. Firstly the local collaborator from each site was asked to provide names of patients who had been recalled to their unit under s37/41. Each identified patient's Responsible Clinician was asked to confirm that the patient had capacity to give informed consent, and that there were no other concerns that might preclude their parent(s) being approached. Twelve patients were nominated by local collaborators as fulfilling the criteria for the research. Of these patients, two were found not to meet all the criteria (not in contact with parent or parent deceased); and five refused to give consent. Three of the non-consenters were White British and two from black and ethnic minority groups. Although they were not asked why they refused consent, three patients volunteered that they did not want their parent to be "bothered". Perhaps consent levels might have been

improved if the study had been explained to patients by a trusted member of staff, although this could be construed as coercive. Five patients agreed that their nominated parent(s) could be contacted, one nominating both parents who were interviewed separately. Although there was some overlap in the accounts of these last two participants, they provided different experiential accounts in terms of their focus and emphasis, as would be expected from a phenomenological perspective.

It was made clear to patients that giving or withholding their consent would have no influence on their care and treatment. It was vital that as detained patients they had a full understanding of this issue and did not give consent because of any belief that this was a requirement of them. They were “given ample opportunity to understand the nature, purpose, and anticipated consequences” of the research project (British Psychological society, 2009, p.12). Consenting patients were asked to sign a consent form and asked to nominate one or both parents to take part in the study, and provide contact details of the nominated parent(s).

The nominated parent(s) were then contacted by letter, explaining the purpose of the research and inviting them to take part. They were sent a reminder letter if they had not responded within four weeks. All of the parents contacted agreed to be interviewed about their experiences and a mutually convenient time and place for the interview arranged.

Table 4.1 highlights the variation in the patient group in terms of time spent in the community as a conditionally discharged patient before recall, and length of time in hospital since recall. Although there is some variation in the length of time between

the son's discharge and recall, and the length of time since recall to hospital, the only notable difference appeared to be for the participant whose son had been recalled more than once. The fact of his conditional discharge following recall may have enabled her to accept this as a feasible outcome. However, his recall on more than one occasion may also indicate that even a subsequent conditional discharge may not be 'successful'.

Table 4.1 Variation in patient group relative to participants

Pseudonym of parent	Length of time between son's discharge and recall	Length of time since son's recall to hospital	No of times son recalled
Clare	3 years and 9 months	1 year and 2 months	1
Brian	1 year	5 months	1
Elizabeth	3 years and 5 months	5 months	1
Trevor	9 months	1 year and 8 months	1
Laura	3 years	5 years	>1
Penny	1 year	5 months	1

4.2.2.4 The sample

All the participants were of white British ethnic origin. Personal details will not be provided for individual participants as this could identify them. All participants were between their late forties and early sixties. Four were in employment, one retired on health grounds, and one has never been employed due to mental health difficulties.

4.2.3 Materials

For the study to proceed, various documents were prepared. These included a letter to the Responsible Clinician for the patients seeking confirmation of the patients' capacity to consent to approach their nominated parent(s); information sheets detailing the study for both patients and their nominated parents(s), and a consent form for patients, which also identified their nominated parent(s) (Appendices 1-4).

At interview, materials used included a consent form for participants and the semi-structured interview schedule. Participants were given information as to where they could find help and support following the interview if they felt that this would be of benefit to them (Appendices 5-7). In order to conduct the interviews and transcribe them, equipment included a hand held digital voice recorder; headphones, and a computer which was used during the transcription process and while writing up the research.

Participants were offered choice of interview location; at the forensic unit in a location away from the ward areas, or at a location of their choice. This was in order to enhance participant choice and control within the research process with the aim of minimising any power differential inherent in the researcher-participant relationship. If the participant chose to be interviewed at their home, lone working procedures were followed to ensure safety.

4.2.3.1. Development of the semi-structured interview schedule

The semi-structured interview schedule was developed to enable an exploration of the experience of having a son conditionally discharged and then recalled to hospital under s37/41. Smith and Osborn (2008) highlight the need for the interview to be “guided by the schedule rather than be dictated by it” (p.58). Using a semi-structured interview schedule allowed the participant some freedom in how the interview proceeded, thereby not limiting issues to those predetermined by the researcher.

Previous research has identified significant domains for parents of sons referred for forensic psychiatric treatment, up to and including admission (Nordström et al., 2006). The research question aimed to extend previous research by exploring the experience of parents beyond the admission phase. Therefore the schedule questions related to the conditional discharge and recall phases, as well as the admission phase. The rationale for including questions regarding the admission phase and not limiting them to the phases under investigation was twofold. Firstly, it was hoped that questions about admission would orient participants to their experiences; in particular as they recalled their thoughts and feelings as conditional discharge was being suggested by the team. Secondly, as conditional discharge and recall relate to being in the community and hospital, the possibility of these reflecting parents’ experience of the earlier pre-admission and admission phases was considered. Thus in order to enable parents reflect on their experience, questions related to all stages of the process including admission, conditional discharge, and recall.

The schedule also acted as an aide memoire to ensure coverage of aspects which had been highlighted by the literature as relevant to parents such as their concerns, the effect on their own lives and their relationship with their son. Questions were designed to be general in order not to direct the participant, such as 'how did you feel about (admission / conditional discharge / recall)?', and 'how did you manage (feelings identified by the participant)?' During the interviews it was rarely necessary to refer to the interview schedule other than to check that areas had not been missed. This is in line with semi structured interviewing in IPA which is deliberately designed to be as non-directive as possible so as to avoid eliminating new and unexpected themes at source. The interview could be described as a conversation between the parent and the researcher, with the researcher asking for clarification or development of the parent's account. Finally, parents were asked if there was anything they wished to express that had not been already covered. The semi-structured interview schedule (Appendix 6) guided the interview process; however the participant influenced how the interview proceeded.

It is possible to see from the transcripts how the guiding questions in the semi structured interview developed into a discussion around a broad range of material which included aspects of parents' relationship with their son throughout his life.

Questions were phrased in an open-ended manner in order to elicit rich narratives from participants. For instance, when asking about conditional discharge, one question was: *how did you feel about the conditions of discharge?* IPA methodology aims to facilitate the researcher's attempt to enter the world of the participant. Too

many specific prompts may lead the participant (Smith & Osborn, 2008) and were therefore used sparingly. Probes were used to clarify questions, or to encourage expansion on a topic, for example by repeating a word that they may have used to encourage them to expand on this, or by questioning '*can you tell me more about that?*'

The interview schedule was piloted with a parent of a patient who had been conditionally discharged, although he had not been recalled to hospital. The pool of participants was known to be small and if extensive changes were to be made to the interview schedule, this would further limit the number of potential participants if they were used in the piloting phase. For the pilot interview the recall questions were therefore eliminated. The pilot interview enabled the testing out of the schedule. At the end of the pilot interview, the participant was asked to provide feedback regarding the questions in terms of clarity and content, and also regarding the interview process. The participant said that she felt that she had been given the opportunity to reflect on her experience of both the admission and conditional discharge phases, and that the interview schedule had facilitated this. She did not offer any suggestions as to No alterations were therefore made to the interview schedule, although during this interview she was noted to frequently relate how she thought her son might have thought and felt, rather than directly referring to her own experience. In the light of this, participants in the study were reminded that the questions related to their own experience rather than that of their son.

4.2.4. Procedure

Interviews were held at a location of the participant's choosing. All participants but one elected for the interview to take place in their home. The other participant requested that he be interviewed at his place of employment. Participants were advised that the interview would take approximately an hour, and that they would be offered time to raise any questions regarding the research, or issues arising from the information sheet and consent form.

At the interview, participants were again given the information sheet which outlined the research aims, and explained how the interview would proceed, including how it would be recorded (Appendix 3). Prior to completing the consent form, they were again offered the opportunity to ask any questions or raise concerns. Participants were provided with a directory of support (Appendix 7) in case the interview raised issues for them about which they felt that they would like to seek further support. The interview started after the consent form had been completed. Questions were guided by the semi-structured interview schedule and interviews recorded via a hand held recorder placed between the researcher and participant. Interviews lasted between 67 to 84 minutes. Following the interview, participants were debriefed and given time to reflect on the interview process. Consent to include their interview data was confirmed. All six continued to consent, although the recording would have been deleted at this stage if they had requested that their data was not included in the study.

4.2.5 Data analysis

This section highlights the analytic steps used to analyse the six interviews. It focuses on transcription and the steps of IPA as summarised by Smith and Osborn (2008).

4.2.5.1 Preliminary analysis

One of the first stages of qualitative analysis is the transcription of the data. I transcribed all of the interviews in order to start to engage with the data. This helped me get a real sense of the interview data and immerse myself in the transcripts. I transcribed interviews verbatim, taking account of non-verbal features such as emphasis that participants placed on words by using a bold font; noting pauses; and other aspects of non-verbal communication such as laughter. Transcription took between twelve and sixteen hours for each recorded interview. The transcription process took longer when participants spoke quickly or quietly.

For research that adopts a design of interviewing a number of participants, Smith and Osborn (2008) recommend looking for themes in the first case, focusing in detail on the transcript of one interview in order to gain an in depth understanding of the phenomenological experience of the participant. For this study, I read the first transcript several times before adding two columns to the transcript. In the left hand margin I made notes; commenting on the data by paraphrasing what had been said, summarising, or making potential associations. It was at this stage that I started making preliminary interpretations. I completed the whole transcript in this way before resuming at the beginning to document emerging themes in the right hand

margin. It was during this subsequent reading of the transcript that I drew on my own interpretative resources in my attempt to make sense of what the participant was saying.

4.2.5.2 Looking for themes in the first case

I attempted to transform notes made in the left margin into concise phrases, while being mindful not to lose the original quality of what was in the text (see Table 4.2 below and Appendix 12 for fuller example. The appendices include examples of the various stages of analysis as relating to one participant, Clare). This process involved shifting towards a more abstract level, and the use of more psychological terminology became evident. I continued to check the thread between my sense-making and the original data.

Table 4.2 Example of 1st coding within an individual transcript (Clare)

Initial analysis	Transcript	Emerging themes
Suspect deterioration	When I first began to suspect it. I	Uncertainty
A lot to lose	didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try	Loss of progress / hopes for son
Trying to contain things	and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding.	Responsibility assumed by mother

4.2.5.3 Connecting the themes

I then listed all the themes that had emerged (Appendix 13). Having listed the themes I began to look for possible connections between them. It appeared that some themes clustered together while others emerged as super-ordinate concepts (Smith & Osborn, 2008). Throughout this process, I continued to check that the connections I was making reflected the interview data. Smith and Osborn (2008) refer to this part of the analysis as “iterative” as the reader interacts closely and repeatedly with the text. For example, themes of fears realised, fear of violence, fears dismissed by others, fear of madness, fears unvoiced, fears for son, clustered together into a super-ordinate theme of “fear” for the first participant, Clare. Another super-ordinate theme of optimism / hope included “seeing the positives, hope with finding a solution, false hope, and realistic hope”. At the end of this stage, I produced a table of first coding super-ordinate themes, also listing the sub-ordinate themes which were referenced by the line number in the interview (Appendix 14). I also took note of my initial impressions, the tone of the interview and points of interest. Appendix 15 gives all themes and quotes relating to this stage of coding.

4.2.5.4 Continuing the analysis with other cases

I analysed each of the interviews on a case-by-case basis; all of them subject to the same interpretive process as described above. I used super-ordinate themes that had emerged from the first interview to orient analysis of the other transcripts.

However I was careful to remain faithful to the data and acknowledged new issues which arose, while also identifying patterns of response (Smith & Osborn, 2008). IPA is a cyclical process (Smith, 2007); therefore, when new themes emerged from later transcripts, I went back to previous interviews to see if they were also represented there. This meant I was constantly returning to the transcripts, re-visiting phases of the analysis, and re-evaluating super-ordinate themes.

Once I had analysed each transcript by the interpretive process and a table of super-ordinate themes produced for each participant, I went back through each transcript to summarise what appeared to me to be the main themes for the different phases which participants had spoken about; pre admission, admission, conditional discharge, recall and the future (Appendix 16). The data was so rich and complex, that I felt I needed to stand back from it and reflect on the main themes for participants for each of these phases. Revisiting the data in this way enabled me to produce a second coding and organise the themes into a coherent framework for understanding the participants' experiences. This stage in the analysis was a challenge for me both in terms of time, and also through continually checking that the themes were grounded in the data. Table 4.3 gives an example of this analysis (for a fuller example see Appendix 17; Appendix 18 for table of 2nd coding super-ordinate themes, within which sub-ordinate themes were listed and referenced by the line number in the interview; and Appendix 19 for themes and quotes relating to this second coding phase).

Table 4.3 Example of 2nd coding within an individual transcript (Clare)

Transcript	1 st coding themes	2 nd coding themes
<p>When I first began to suspect it. I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding</p>	<p>Uncertainty</p> <p>Loss of progress / hopes for son</p> <p>Responsibility assumed by mother</p>	<p>Emotional Impact: Process of fear-hope-loss</p> <p>Infantilisation vs. autonomy / progress to independence</p> <p>Responsibility: parental: doing what I can</p>

I analysed all the transcript data regardless of phase in order to ensure that nothing was lost by ignoring data from the pre admission and admission phases. There was a lot of rich data from these phases, but I decided to eliminate this from the current analysis as the experience of conditional discharge and recall was the phenomenon under investigation. I again checked the superordinate themes and dropped those which although pertinent to the earlier phases of admission, did not illuminate the conditional discharge and recall phases. Finally, I produced a master table of the themes and super-ordinate themes relating to the participants' experience of the conditional discharge and recall phases (Appendix 20).

Four super-ordinate themes emerged from the analysis of six participants, with twelve sub-themes identified.

4.3 Ethical considerations

Ethical approval was granted by both the University of East London School of Psychology research Committee on 28th April 2010. (Appendix 8) and the National Research Ethics Service in October 2010 (Appendix 9). The secure units in the study were based in the South-East and ethical approval was also sought and obtained from both Kent (Appendix 10) and Oxleas (Appendix 11) Research and Development departments. The research adhered strictly to all ethical principles for conducting research as outlined by the British Psychological Society guidelines (British Psychological Society, 2009).

4.3.1 Potential distress

Participants were asked about an experience which may have highlighted issues that have been and may still be difficult for them. Willig (2008, p.19) notes that “researchers should protect their participants from any harm or loss, and they should aim to preserve their psychological well-being and dignity at all times”. Black and Black (2007) make the point that the vulnerability of participants needs to be balanced with respect for their autonomy as research participants. Brabin and Berah (1995) interviewed parents of stillborn children ending with questions about the distressing nature of the interview. They found that although most participants did

not find the interview distressing, even those who did find it helpful. Becker-Blease and Freyd (2006) in addressing concerns of researchers who ask about abuse note that “eliciting distress is not confused with causing psychological harm” (p.222). Interviews were conducted as sensitively as possible, not by avoiding sensitive subjects, but by treating participants with respect and autonomy. Participants were provided with a list of resources whereby they could access help and support should they wish to do so following the interview.

4.3.2 Informed consent

Restricted patients are by virtue of their legal status limited in their exercise of freedom. It was therefore important to ensure that they had capacity to consent, and that that they understood that their refusal to nominate a parent for the purposes of the study would have no impact on their care and treatment. Capacity was determined by their Responsible Clinician. The consent form made it clear that refusal would not affect them in any way. Similarly, I was mindful of the possibility that parents may be concerned that their refusal might adversely affect their son’s care and treatment. Participants were advised that their agreement or refusal to take part would have no impact on their son’s care, treatment, or care pathway. They were advised that they were free to withdraw at any time and to decline to answer any question put to them.

4.3.3 Confidentiality

The small numbers of potential participants arising from a narrowly defined service inevitably raises the issue of how their responses can be kept confidential. Participants were given a pseudonym together with an identifying number which was

used for the transcript and any documents relating to the analysis. Any information which might have led to identification of participants or anyone named during the interview was anonymised. Pseudonyms were used in the results section of the study. Participants were provided with a detailed account of what would happen to their data.

All tapes, transcripts, and participant data were stored either in a locked cabinet, or on a password protected computer. Consent forms were stored in a locked drawer separately from the transcripts. This storage location was situated within a secure building, itself within a medium secure unit. When transcripts had been analysed, they were also stored in separate secure filing cabinet. On completion of the research, all recordings and transcripts will be deleted.

Participants were reminded of the limits of confidentiality, namely that this would only be breached if they made a disclosure that led the researcher to believe that either they or someone else could be at risk; or they disclosed any issue that might threaten the security of the hospital unit where their son was a patient. The participant was informed that in the eventuality of either of these occurring, the specific issue would be discussed with them; and the Responsible Clinician of the patient would be advised. However, no such issues arose.

4.3.4 Offering payment

Tyldum (2012) has highlighted that any pressure to participate in research is an exercise of power and that monetary incentives as a motivator to participate will interfere with the ability to freely consent. However, in this study the financial reward was relatively low and unlikely to have exerted undue pressure on the participants, who all expressed their readiness to take part.

4.4 Validation of the analysis

Yardley (2008) has suggested guidelines to enhance the validity of qualitative research including using a research diary. By keeping copies of all the stages of analysis, the resulting audit trail supports a transparent process whereby others can see how the interpretations have been arrived at; “linking the raw data to the final report” (p.243). I kept records of the differing analytic stages, from the comments on the interview transcripts, right through to my considerations as to how the themes may link together. I was thus able to go continually back to the data to check that my analysis was grounded.

For any qualitative research to be valid, the analysis must be systematic and grounded in the original data. Although the interpretations were inevitably influenced by my own values and beliefs, interpretations must be grounded in the data. One of my supervisors read through the interview data to check that themes and super-ordinate themes in my final analysis did indeed reflect the accounts that parents had given. The process of data collection as described in 4.4.5 also helped me to

become aware of my biases and assumptions. There is no “right” or “wrong” analysis, rather the aim was to It is important to note that the aim is not to produce a “correct” analysis but to create a description of the phenomenological experience fully grounded in the data.

In terms of reflexivity and openness, there were a number of themes that were unexpected. Given the nature and purpose of conditional discharge, I was surprised to find that parents still found that their concerns about their son were not taken seriously by the supervising team or that they seemed uncertain as to where the boundaries of responsibility lay. I had also not previously been aware of the importance that parents attached to their son’s “innocence” by virtue of his mental health. I had foreseen that parents would experience loss and grief when their son’s mental health deteriorated, but their reappraisal of what they expected him to subsequently achieve demonstrated a resilience and positive attitude that was stronger than I had anticipated. I had wondered whether confidentiality would be an issue, but this was not directly raised by parents, possibly because of the purposive sampling; sons who agreed that their parent could be approached perhaps also agreeable to them being provided with information.

5. Results and analysis

This chapter presents the findings of the study. A number of themes emerged from parents' accounts of their experience of having a son conditionally discharged from hospital and then recalled to hospital under s37/41. The main themes relating to this experience as highlighted in the study will be presented and discussed. Table 5.1 below summarises the super-ordinate themes together with the component sub-themes. It will be indicated in the text as to where themes relate to either conditional discharge or recall or both. Each theme will be discussed in turn, illustrated by quotes from the parents who took part in the study. The quotes offer examples of how the themes are grounded in the data.

Table 5.1 Super-ordinate and sub-themes

Super-ordinate theme	Sub-themes
5.1. Emotional impact	5.1.1 Hope and Reappraisal 5.1.2 Fear and Loss 5.1.3 Identity
5.2. Responsibility	5.2.1 Parents assume responsibility 5.2.2 Autonomy vs. Infantilisation; Progress towards independence 5.2.3 Uncertainty as to who is responsible 5.2.4 Blaming and feeling blamed
5.3. An impenetrable system	5.3.1 Shut door 5.3.2 Engulfed 5.3.3 Open door
5.4. The expert system	5.4.1 Professionals' assumed expertise 5.4.2 Not treated as equals

This study highlights the experience of parents of sons who have been conditionally discharged from a medium secure hospital into the community; but subsequently recalled to hospital under s37/41. Although all themes relate to this specific situation, a distinction could be made between their own psychological responses to that situation, and how they perceive the forensic mental health system. However, this distinction would be artificial as their experience of the forensic mental health system clearly also had a profound psychological and emotional impact on parents. Parents' experience in this study will be discussed in terms of the emotional impact on them (5.1); both in terms of a cyclical emotional process and also in relation to their identity as a parent. Interwoven throughout the accounts is a sense of ongoing responsibility for their sons (5.2). Parents hoped that their sons would achieve independence, and looked for signs of progress, while recognising that their sons may never reach full independence. Particularly during the conditional discharge phase, parents seemed to be uncertain as to who should be taking responsibility for their son and to what extent. Although health and social care professionals are involved because of their statutory responsibilities, some parents remain unsure as to where these boundaries lie, and feel isolated and unsupported. Some parents may feel blamed by the clinical team for the failure of the conditional discharge. In turn they strongly voice their blame of the professionals when their son deteriorates. This leads on to a superordinate theme describing their experience of the mental health system as impenetrable (5.3). Despite their son being well known to the mental health system, parents feel effectively shut out when they try to seek help for him. They cannot understand such a system which appears to operate under different rules from the world they usually live in. Once their son has been recalled they highlight how they feel he now belongs to the system and there is a sense that

he is engulfed by it. Feeling excluded from mental health services; parents seek help from others who they perceive are there for them. Finally, parents express an experience of the forensic mental health system as an expert system where their knowledge of their son is marginalised and they are not valued (5.4). Despite their concern for their son and desire to help him, they feel that they are not treated as equals.

5.1 Emotional impact

The super ordinate theme “Emotional impact” reflects the emotional impact of having a son conditionally discharged from a forensic unit and subsequently recalled. It reflects how parents’ internal worlds changed and adapted during the process of conditional discharge and recall both in terms of the relationship with their son, and the relationship with themselves through their identity. Parents experienced an overarching process of hope, fear, and loss, which appeared to fall into two sub-themes which reflected the positive and negative aspects of this process. Both sub-themes entailed an emotional journey. It seemed that parents felt that their identity was defined by their son’s identity as a mentally disordered offender, but resisted this by challenging the forensic label.

5.1.1 Hope and Reappraisal

At the point of conditional discharge, parents expressed both pleasure and hope that their son would continue to progress in the community. When their hopes of progress were not realised, parents formed a more realistic appraisal of what could be hoped

for, and following recall were able to reflect on and take pride in what he had actually achieved.

Parents in this study had expressed that they felt relief when their sons had first been admitted to forensic medium secure services in that he was finally getting the treatment that he needed. The push towards community care and the closure of local psychiatric beds has meant that patients admitted informally or detained under civil sections in local hospitals often have short admissions and treatment is mainly via medication and nursing care. The resources available to forensic medium secure services are extensive in comparison, with multidisciplinary teams providing a wide range of treatments. Parents' pleasure at the prospect of their sons' conditional discharge may reflect both the perceived success of the treatment and also the end of a lengthy admission:

Elizabeth: I was really pleased then because I thought he'd, you know, he'd done anything he was going to do in there and they got to the bottom of a lot of things, and you know, it's time to, I thought it was right that he was discharged then (350-353)

Penny: we were really pleased because [...] it was quite obvious that he was completely well; so it was, it was fine; there wasn't any problem at all and it was, yeah, let's get on with it sort of thing (441-443)

After their sons had been detained for longer than they had anticipated, parents were pleased when their son was conditionally discharged and there was a sense of hope and anticipation. Parents used phrases such as feeling "over the moon" when their sons were conditionally discharged. Elizabeth described feeling positive that the [team] had addressed and improved her son's psychological well-being. In the

second quote, Penny (above) described her feeling that discharge was appropriate because her son had apparently made a complete recovery and there was nothing further to be gained by prolonging his admission.

Hope was revealed in various forms across the narratives. Once their son had been conditionally discharged parents were hopeful that their son would progress towards an independent life:

Elizabeth: he started going to college, joins football clubs wherever he goes, [...] and he got a gym membership and I did think [...] that he would have progressed along those lines and even back at that point I thought he'll become more self-sufficient, you know, and move on to, like supported housing as they do (360-368)

Here Elizabeth was realistic in her appraisal that her son would not achieve sporting greatness, but she could see how his gradual reintegration into the community through his sporting interests could help him in both his personal and interpersonal recovery.

Laura: at this stage I was hoping for a, a little steady job for him, you know, something that he could actually cope with and hold down [...] I just wanted to play it all by ear, deal with it stage by stage, as something come along you deal with that, and then, it's time to go on to the next, you know; perhaps this could happen, you know? (353-358)

Laura was uncertain as to exactly how much her son would be able to manage in the community and wanted him to take it a step at a time. Her use of the term 'stage by stage' suggests that she was expecting some change. She didn't want him to take on too much all at once but hoped that he would be able to hold down a 'little' job.

Trevor: I thought [...] well he's out now, they just let him go and, and hope for the best. Which is what [...] I did as well you know (696-698)

Rather than looking for concrete examples of progress, Trevor relied on a vague 'hope for the best' attitude. It seemed as though there had been no discussion with Trevor about the pathway or progress the clinical team planned or expected for his son prior to conditional discharge.

Parents trusted that the discharge conditions would be protective and containing. There was a sense of gratitude that others now had some responsibility in on-going care and supervision:

Clare: I thought that [S41] wasn't a bad thing, because I thought he's not going to be able to come out and then do his own thing; there's always going to be someone keeping an eye on him and saying, you know, "Fine as long as you're taking your medication and you're well, that's fine, we'll leave you alone, but if you don't then we're on top of you and we'll have you back." And I thought that was a good thing (120-126)

Brian: we were actually sold that the 41 was going to care for him best because they would have to look after him afterwards (453-454)

Prior to his conditional discharge Clare viewed the conditions of discharge positively in terms of their containing effect on her son. She envisaged that he would be allowed relative freedom if he abided within the constraints of the conditions, and that this would be in his best interests. Brian acknowledged that the team's positive description of the restriction order in terms of ensuring ongoing care once his son

had been conditionally discharged was true, but his use of the term 'sold' may indicate that he felt that he was only provided with positive aspects as seen from the team's perspective.

Following his conditional discharge as their son's mental health deteriorated, parents described feelings of fear and loss described in the next theme. However these feelings were accompanied by parents developing a more realistic appraisal of what they could hope for:

Clare: And I think when I saw him backsliding, I knew, so there was a lot of coming to terms with it then and accepting that (659-660)

Clare's description of the period in the community while her son was becoming unwell indicated that she had to come to terms with the fact that he would not continue to progress and that this understanding was a process that took some time. However her reappraisal of what he could achieve was reflected in her later account after he had been recalled where she had come to an acceptance of his lifestyle:

Clare: As far as I'm concerned, if I knew, there was no question of him drinking and I knew there was no question of his not taking his medication, then I wouldn't worry about him. I know he'd still be disorganised, I know he'd, he'd live in a degree of chaos, he wouldn't do the washing up after his meal, and he would probably get into a mess with his money now and again, but I think, you know, he could manage all right (720-725)

Clare amended her hopes and expectations of her son in the light of her experience of his conditional discharge into the community. She differentiated his 'disorganised'

behaviour which she thought would not worry her, from that which could precipitate deterioration in his mental state which would cause her to worry about him.

Reappraisal of their expectations of what their son might manage was associated with parents expressing pride in what he had achieved:

Laura: I'm equally as proud with [son and daughter], they both overcome things to get where they are, you know? So you know they, in different ways, but they've both achieved things (133-135)

Laura had previously described her hope that her son would become an engineer. She now saw his achievements in terms of overcoming his mental health difficulties, which gave her a sense of pride in him.

5.1.2 Fear and Loss

Parents' optimism when their son was conditionally discharged was tinged with fear that things may not work out. They remembered how he was before admission and worried about whether he would act in ways which could precipitate deterioration. The spectre of recall hung over them and there was a sense of inevitability that this would happen. For example Clare expressed fear when her son moved to a community placement where he was not constantly monitored:

Clare: I was scared. And I also, because he's so disorganised and chaotic, I was concerned about him with budgeting issues and whether he'd [...] be able to cope financially. (393-401)

Later in the transcript she expressed another concern she experienced prior to his conditional discharge:

I think that, that was a worry when he was being discharged, that was one of my worries, one that he would stop taking his medication and the other thing was whether he would go out drinking (698-700)

Clare knew her son and recognised that he may not only be disorganised and therefore have practical difficulties, but feared that he may stop taking his medication. This scared her as she remembered how he was before he was admitted to hospital and the impact it had on her and her family.

Parents were anxious about their son and whether he would manage in the community once conditionally discharged:

Trevor: I was anxious about him because you always get this niggling feeling at the back of your mind that "Is he going to make it?" (425-427)

Earlier in the transcript Trevor had described another aspect of this concern:

I always feared that he would be recalled, yes. Because John's relatively unstable (179-180)

Like Clare, Trevor linked his fear about his son being able to 'make it' out of hospital with his knowledge of his son, in this case, his son's instability. There was a different intensity of emotions among the narratives; Trevor was not 'scared' like Clare, but experienced an ever-present anxiety and concern about his son.

When parents saw signs of their son's deterioration during his conditional discharge, they managed their anxiety through rationalisation or avoidance, hoping that these signs were a 'one off':

Clare: the first few danger signs I tried to rationalise, you know, and think perhaps I'm imagining it and I'm sure he's all right, and he'd come back and he'd seem to be OK. I used to talk to him about it, when he was first beginning to backslide he would reassure me and say, 'No, no, it's all right Mum, OK, yes I've been drinking a bit much and I'm not going to', and put my mind at rest (215-220)

Trevor: do tend to sort of bury your head in the sand, and my sort of thing is 'oh well, it's only a one off, he won't do that again' (751-752)

Both Trevor and Clare sought reassurance about their son's possible deterioration, Clare directly from her son, Trevor through internal means; he avoided the prospect of having to consider that his son was deteriorating, by telling himself that it was a 'one off'.

Reassurance was short lived however and once parents saw their son becoming unwell in the community, their unease escalated to fear as their potential concerns were actualised. Parents feared for the safety of others, their son, and themselves, which heightened their awareness to danger. Fear turned to terror if the threat was directed directly at them.

Laura: everything is just a dream all the time...you're running on a treadmill all the time, just er, what's he gonna do next, and er what's going to be the outcome of that (253-255)

Earlier in the transcript she had given an example of when her son was unwell during his conditional discharge:

He come downstairs and, [...] he found a hammer and I'd just had the kitchen all put in, and he said 'I'll smash all this up', cos he didn't want to hurt me you see. He said, 'I'll smash all this up' so I said to him 'well go on then'; cos I thought 'you're not going to intimidate me Peter and don't think that you're gonna do it'. At that he came rushing out to the garden and chased me with the hammer [...] oh it was terrifying (198-210)

Laura described her situation as 'running on a treadmill', which suggests a sense that there is no brake or escape and as noted above, it felt like a dream (or nightmare). She had no idea what her son would do, although she felt he would not hurt her which gave her some strength in that she refused to be intimidated. When he tried to attack her, even that assurance disappeared and left her terrified; she had no idea what he would do. Her worries escalated when she thought that his safety was at risk:

I thought they was going to find him dead in the morning. I really was, I was in a dreadful state. I drank a bottle of brandy that night, and I don't drink. You know? I was in such a State (503-505)

This level of uncertainty became intolerable for her, and Laura used coping strategies she had never used before, possibly to block out her unbearable feelings.

Parents described a sense of powerlessness to halt their son's downward slide during the conditional discharge phase, which led to resignation; best illustrated by

Trevor:

I worry about him all the time [...] It's a very worrying experience. The thing is, [...] at the end of the day, there isn't very much you can do [...] because, other than being concerned, you're completely defenceless, you can't do anything (492-503)

Trevor not only felt powerless to intervene in his son's deterioration, there was a sense of him being exposed to the pervasive worry he felt about his son without any protection. Clare echoed this sense of powerlessness:

Once he was on his own, and mentally in that state, of course he wasn't eating; he wasn't washing his clothes; he wasn't washing himself. It was just gross, you could smell him coming up the road; it was just horrible [...] it was heart-breaking; it was distressing. And you know there's nothing you can do, I mean he's in his 20s; and then he wasn't going to pay any attention to me (428-433)

She later described the effect this had on her:

In the end, we just all had this fatalistic, well, you know, whatever happens will happen (552-553)

All Clare felt she could do was watch her son's physical and mental deterioration. Her use of the words 'gross' and 'heart-breaking' imply her disgust of his presentation, combined with agony at seeing her son so unwell. Her powerlessness to intervene led to a resigned, fatalistic attitude. There was irony in her acknowledgement that although in his twenties and therefore unlikely to pay attention to her, he was not taking care of himself

When parents realised that their son's mental health was deteriorating, despite him being conditionally discharged, they felt an acute sense of disappointment and loss, both of their relationship with their son and of the hopes they held for him; a time of grieving. Clare described this as a 'bereavement':

I think there is a grieving, a time of grieving where you come to realise that your child is never, never going to be [...] a normal, uncomplicated, unworrying sort of person [...] You look back at them as children, babies, toddlers and you think, so yeah, there's the death of all the hopes that you had for them, the hopes and the expectations and you realise that's not going to happen [...] it is a bit like a bereavement (643-662)

This grieving process was associated with feelings of grief for the loss of the hopes and expectations she had for her son, linked with a growing realisation that he would never be 'normal'.

Parents described a mixture of relief and disappointment when their son was recalled:

Trevor: I was relieved inasfar as I thought well he's safe in here at least, but very, very disappointed. Yeah, without any question (780-781)

Trevor was disappointed that his son was no longer free and independent but no longer worried about his son's safety or what he might do. These complex feelings characterised the emotional impact of the whole process on parents. Hope and fear combined at the point of discharge, while the loss and grief experienced when their son deteriorated during his conditional discharge was ultimately associated with a

reappraisal of expectations once he was recalled. The course of hope, fear and loss was seen to characterise the whole admission, discharge and recall process.

5.1.3 Identity

The parents in this study described a fundamental shift in their own identity once their son was detained in forensic services. During both the conditional discharge and recall phases they described seeing themselves as defined by professionals in terms of their son rather than a valid person in their own right. Given that parents had often fought to try to get their son help, their feelings of being marginalised in this role were heartbreaking. Clare felt this acutely during her son's conditional discharge:

I was really much more of a 'oh, it's that, it's Michael's mother again', you know, 'you deal with her this time', I can just hear them saying it (623-624)

When trying to enlist the help of the community team once she saw her son deteriorate, Clare perceived that she was viewed by them not only as just her son's mother, but as a nuisance that no one wanted to be bothered with.

There was a sense that parents resisted this assault on their own identity by challenging the foundation of their son's identity as a mentally disordered offender. Throughout the admission, conditional discharge and recall process, parents highlighted how the index offence and consequent forensic involvement in their son's care was something that could have been avoided if mental health services had been more responsive to their concerns.

Penny: I'm resentful of the fact that he's tied into the Ministry of Justice with a section forty-one and it should never have happened if somebody had listened to us (271-272)

Brian: when they justify why they're doing things, sometimes it's almost as if well you know, he's a criminal, so of course we can do this. And then we say no but he was found not guilty. Oh well, that doesn't make any difference. Well it does make a lot of difference to us (480-482)

Penny and Brian's account relate to their son's recall to hospital although the transcripts indicate that they felt similarly throughout the whole process of admission, conditional discharge and recall to hospital. Penny felt angry with a system that was unresponsive, believing that her son would not have offended if her concerns about him had been listened to. Consequently much of her account was concerned with her struggle to accept her son's identity as a mentally disordered offender and the involvement of the Ministry of Justice. Brian also felt that his son's verdict of 'Not Guilty by Reason of Insanity' was crucially important, and could not understand why professionals could not appreciate this.

5.2 Responsibility

The superordinate theme of "Responsibility" reflects the uncertainty as to who holds responsibility and / or power at any time. Throughout the whole admission, conditional discharge and recall process, parents feel responsible and do what they can for their son. At the point of conditional discharge parents feel some reassurance that mental health professionals will share this responsibility. However, despite such

assurances, in practice parents feel that they are left to shoulder the load. They describe feeling isolated and unsupported and unsure of who to contact and what to do when their son's mental state deteriorates, together with ambivalence about recall. After he has been recalled parents feel blamed for things going wrong during conditional discharge, and reciprocate by blaming mental health professionals. Although parents want their son to be independent, once he has been recalled they acknowledge that they will always feel some responsibility for him.

5.2.1 Parents assume responsibility

Parents in this study assumed a high level of responsibility for their son throughout the whole process and did what they could to help him, materially, emotionally and on a practical level. As he deteriorated during his conditional discharge their support increased in intensity, until finally there was a sense that they just became resigned to the situation.

Clare: he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful (206-208)

Later in the interview she added

That was one benefit of him being recalled; he handed over his bankcard to me and gradually over the next year or so I eliminated his overdraft, and I just give him a certain amount of cash every week (402-404)

Perhaps reflecting her optimism for her son's future when he was conditionally discharged, Clare invested materially for him when he moved into his own flat. It was almost as if she took on some of the caring responsibilities she provided for him before he was hospitalised, doing what she could practically. Her account elsewhere described how she felt powerless to help her son as his mental health deteriorated. Once he was recalled, she was able to take back some practical responsibility for him. Nevertheless, she was only able to do that which he permitted her; she could sort out his financial situation because he gave her the power to do so.

Parents also tried to help their son by taking some responsibility for his wellbeing, supporting him emotionally:

Trevor: all I can do is encourage him to, just to do what he does best [...], but other than that there's nothing else you can do, so although the concern never goes away, worrying is just going to get you nowhere (524-530)

Trevor recognised that worrying about his son did not achieve anything or help his son in any way. Although he had described practically supporting his son during the conditional discharge phase, this account referred to the time after his son had been recalled to hospital. There is a sense that Trevor felt powerless to offer practical support, and that all he could do was encourage his son, perhaps by helping him see that he did have strengths and abilities despite his failure to manage discharge.

Laura took responsibility for her son's wellbeing by letting professionals know when his safety was compromised during his conditional discharge:

Laura: I found this bag of tablets, and I phoned up his social worker and told him. But he was good as nothing (315-316)

She went on to describe how being unable to obtain any help in this situation made her feel:

I was just so, so, well, frightened, quite frankly, and thinking, what am I going to do now? Here we go again [...] So I made him take his Sunday tablets (398-404)

Laura tried to get help from her son's social worker when she discovered that her son had not been taking his medication. She knew how dangerous her son could be when un-medicated. Getting no response from his social worker, she felt she had to take responsibility herself but did not know what to do. Feeling isolated and unsupported, her fright may have been exacerbated when she was left guessing what might be the right course of action. Having no professional help available she took a medical decision not knowing what the outcome might be.

There is a sense that some parents felt obliged to assume responsibility while their son was conditionally discharged but lack of support could lead to some resentment.

Penny: if he'd stayed in the community as he was, I was going to be having to jump on the train every night, go across and make sure he was all right and come back (673-674)

Penny seemed to recognise that extra resources were unavailable when her son's mental state had deteriorated, and assumed that she would need to meet the shortfall. Her comment indicates that she did not trust the team to provide the help

she thought he needed in the community and that she would be expected to take on this responsibility.

Laura: I know it was all Peter's fault; but angry that there's no-one supporting me. No one there for me, to help me; you know, it was all, all on my shoulders, which is my son, you know, it should be on my shoulders to a certain degree, to get things put right (441-445)

There was ambivalence in Laura's feeling of responsibility for her son when he was conditionally discharged. She did not absolve him of responsibility for the situation when he had stopped taking his medication and felt that it was her responsibility to get things put right. But it was clear that she wanted support with this. She did not feel that mental health professionals had helped her, either for herself or to care for her son. Her sense of isolation in feeling that she had to carry the responsibility on her own without help from professionals led to feelings of anger.

Brian: we were in on the Tribunal situations, we sit on the back row [...] and I'm writing notes galore and the writing's getting bigger and bolder, and passing them to his solicitor and hoping his solicitor does pick up on some of them (894-897)

If their son wishes, parents are permitted to attend statutory meetings, such as Mental Health Review Tribunals, to support him. After his son had been recalled, Brian's description suggests urgency in wanting to get his voice heard; his notes to the solicitor were challenging the powerful voice of the professionals who were recommending that his son was not discharged. He hoped that people with the power he lacked in this situation would take notice of him. Having no voice himself, he had to hope and trust that one who did would act for him in this capacity.

When parents realised that whatever they did, they could not prevent their son's deterioration, there was a process of resignation:

Clare: I suppose it was just thinking well I can't do anything else; I'm doing what I can [...] I think I gave up any idea of trying to make it right because I knew I couldn't, and I just kept every now and then ringing up [local CMHC] and saying 'have you seen Michael? He is really in a bad way; he's not taking his medication' (678-684)

Like Laura, Clare wanted to 'put things right' for her son but despite doing what she could, she realised that she was unable to help him. Recognising that her own attempts to help her son were futile, Clare tried ineffectually to enlist the help of the mental health team caring for him during his conditional discharge by repeatedly bringing him to their attention.

Parents did whatever they could to avert their son's recall. There was a strong sense of ambivalence as to whether they should seek recall:

Clare: when I first began to suspect it. I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding. I mean I always worried about him, so I thought, well even if it does lead to him being recalled (265-269)

Clare was fully aware of her son's history, admission, and lengthy hospitalisation, as well as what she saw as his gains from being conditionally discharged into the community: freedom, relative independence, a flat. She wanted to help him by getting him to take responsibility for his mental state, but the only means at her

disposal was her communication with him. There was a sense of powerlessness that she could not do anything. Her words indicate that perhaps she felt that he could not stop himself from sliding down the slippery slope toward recall either, and the only recourse she had was to try to have him recalled to hospital by those with power to halt his slide.

Brian: We didn't actually want to tell them that we felt he was getting unwell (610-611)

Parents seeking recall, even ambivalently, indicates a measure of trust that the mental health system will benefit their son. Brian did not trust the system sufficiently to do this and so wanted to avoid recall even when his son was unwell. His lack of trust in the team meant that he feared that they might recall him prematurely. Trevor also resisted telling the team that his son was unwell:

I felt like phoning somebody up, but I didn't because I thought to myself, well, you know, if he's going to bury himself, he'll bury himself

Interviewer: *Bury himself?*

Yeah, well when I say, you know, not bury himself, not kill himself, but if he's going to cause himself to be recalled (202-207)

Trevor's reluctance in informing the team of his son's deterioration was associated with his strongly held view that his son should be as autonomous as possible. There was a tension between this view and wanting to help his son.

5.2.2 Autonomy vs. Infantilisation

Although parents wanted their son to be responsible for themselves and progress towards independence once he had been conditionally discharged, they struggled to let go. The shared experience with their son led parents to acknowledge that he may never reach full independence and they described a sense of duty of on-going responsibility. Having expected their son to become autonomous and independent as he grew up, parents were faced with the realisation that this was not happening:

Penny: we went and visited him on Christmas Eve and I went [...] and bought some food and made sure he'd got food in his fridge cos I said to him you do realise that Christmas Day, nothing's open and he went oh isn't it? (556-558)

Penny took responsibility for making sure her son had food to eat; she realised that he may not even be aware that shops closed on Christmas Day. Her question and his answer reflected her increasing awareness of the level of his dependence despite his conditional discharge.

Earlier on in the transcript she indicated that her expectations of him were changing prior to recall:

Penny: when he was ill our expectations were changing because we realised that, you know, he wasn't going to; I mean if he wanted to we'd still support him in whatever he wanted to do. I think he's realised that stress isn't good for him and therefore university wouldn't be good for him.

Interviewer: *Yeah*

I mean I'd quite like him to do it; he, he says he'd quite like to do a course in carpentry or plumbing and get a trade under his belt [...] and I'm not sure that he's actually ready for that yet (519-529).

Her account once he had been recalled reflected her ambivalence; wanting him to progress but feeling that he may not achieve full independence and would require his parents' support in whatever he tried to do. She emphasised that she thought her son also understood this; which may have helped her acknowledge her uncertainty as to whether he was ready to tackle his goal of becoming qualified in a trade.

Trevor also recognised his son's need for his ongoing support in the future:

Trevor: he would need an unbelievable amount of support [...] they survive, usually because their relations back them up [...]. Obviously they can't do anything; they can't go to work [...] they do have some kind of quality of life, even though, you know, they're on medication (437-445)

However later in the transcript added:

He is the only one who is in charge of his own destiny (904-905)

Although Trevor held the notion of autonomy for his son as important throughout conditional discharge and recall, he recognised that this was not really possible and that his son would require a lot of support even just to 'survive'. Trevor's experience of mental health patients appeared to be limited to those whose lives had been

severely disrupted by their disorder. It is possible that he coped with the limitation of his son's autonomy by making downward social comparisons.

Parents also compared their son with their other children:

Clare: And even now I'm aware that I'm never ever going to be able to say 'oh well Michael's fine now, that's it, don't need to worry about Michael any more in the way that I can with the others (314-316)

Clare recognised that she would always worry about Michael in comparison with her other children whom she expected would be independent of her. Her comment indicates that she saw this as a lifelong responsibility.

Parents' limited expectations of their son's independence not only impacted on how they envisaged his future, but also in terms of what he was able to cope with now, having been recalled to hospital:

Elizabeth: I don't want to upset him [...] there's still stuff going on that I ... don't want Malcolm to know about that; still have to protect, well obviously protect him. He doesn't need to know about stuff where he is (782-785)

Elizabeth did not want to burden her son with additional family worries while he was in hospital, but she saw this as her responsibility to protect him from difficulties. Her desire to avoid upsetting him perhaps preventing him from learning to cope with difficulty and thus increase his level of independence.

5.2.3 Uncertainty as to who is responsible

This theme relates to parents' sense of uncertainty as to who actually is responsible for their son when he had been conditionally discharged. Having been led to believe that their son will be well supported and monitored when conditionally discharged, parents are left feeling confused and angry if they perceive that this is not happening.

Laura's comment was scathing:

All the people that were gonna help and all the people that were gonna support me (sarcastically). I had one nurse come round to give him his injection once a week; that was that. Didn't see anybody else [...] other than that it was me and Peter. You know here on our own (219-226)

Laura had been assured that she would not be left unsupported to care for her son who had returned home to live with her when conditionally discharged. The conditions are meant to ensure that the discharged patient remains mentally well and thus reduce risk to the public, which can entail a high level of monitoring and support. The support that Laura's expected did not materialise and she felt let down. She did not even have contact details for the team:

There was nobody else to contact, you know I didn't have a contact number of any sort. Nowhere, nobody. My only contact was the police (261-264)

The unusual nature of her son's situation may indicate that she needed specialist support. She had no idea who she should contact or how, if her son was to

deteriorate or act in risky ways. Having nowhere to go and nobody to turn to suggested her sense of a complete void. She had to use the more general services of the police who would not necessarily know how to advise her. Not knowing what to do or where to turn, there was a real sense of isolation:

I just wanted him to be (...) helped in some way, you know? That's all I wanted, you know, for him to be helped. And no matter where I looked, who I asked, there was nobody could say to me 'Yes, Yes', you know, 'you can do this'. You know, there was no one, it was all if, but, maybe (569-572)

Laura did not feel that she was asking for much; just for her son 'to be helped'. Her account indicates that she sought this help in vain. However it also suggests that it would have been helpful to her just to be encouraged by the team in what she was doing herself. There is a sense that she felt she was operating on shifting sand, with no solidity of a plan of action from the team.

After he was recalled to hospital Penny openly voiced her experience of the ambiguity she felt regarding who should have been responsible for her son during his conditional discharge:

You can't have it both ways guys, it's either you are in charge or you're not in charge. And if you're not in charge why bother even having a section forty one? (747-749)

She saw this responsibility in terms of being 'in charge' which necessarily indicates primacy of responsibility belonging to the team. She was accurate in her perception

that ultimate responsibility was associated with her son's legal status, but there was nothing in her account that suggested the possibility of joint working with the team.

5.2.4 Blaming and feeling blamed

The theme "blaming and feeling blamed" relates to the experience parents had of feeling blamed by mental health professionals both during the conditional discharge phase and when their son had been recalled to hospital. The role is reciprocated as they in turn blame professionals. This unhelpful process only serves to increase the sense of alienation and break down any collaborative relationship.

Taking responsibility opened up the possibility of feeling blamed:

Brian: we got him through the system as far as they're concerned, quicker than anyone has ever done before. And I'll openly say I think they, the professionals there, actually resent that. So when he was readmitted they almost were 'told you so' (559-563)

Brian saw his and his wife's interventions, rather than those of mental health professionals, as facilitating his son's conditional discharge. He then perceived that professionals blamed them for a premature discharge when their son was recalled. It is possible that if he had seen his son's conditional discharge as a shared responsibility between himself, his son, and the team, this feeling of being blamed might have been less strong.

Penny felt directly blamed by the team for not getting things right when her son's mental state was deteriorating during the conditional discharge:

They were saying to me "Oh you've, you, you didn't get it right again" [...] it was my fault and yet I knew that I'd phoned his psychiatrist's secretary, left a message to say he was unwell, had spoken to the CPN [community psychiatric nurse] [...] but they didn't go and see him (727-733)

She voiced a sense of injustice that although she shared responsibility with the team for her son, they did not bear their own responsibility and then blamed her for not telling them he had deteriorated.

Parents were already trying to manage the double burden of having a son who was not only mentally ill, but who had also committed an offence and detained in a medium secure setting. There is a sense that feeling blamed by a system, experienced as unsupportive in this already difficult situation, was so intolerable that parents retreated into a defensive position from where they launched a counter attack:

Clare: somebody said to me 'and if you thought he was not taking his medication would you say or would you keep it to yourself?' And I said 'no, I'd say'. I would, and I did say, and I said and I said and I said and nobody would listen (261-263)

Clare's commitment to taking responsibility for telling mental health professionals if her son was not taking his medication was questioned by them prior to his conditional discharge. Her subsequent actions during his conditional discharge, emphasised by her repetition of "I said", proved her reliability. Yet the mental health

system which questioned her appeared not to bear its own part in this process. She was left blaming a system where there appeared to be no one specifically accountable.

Not only were the professionals blamed for not listening to parents, they were blamed for actively harming the patient:

Penny: they had this emergency CPA [Care Programme Approach] meeting and he was so frightened and stressed about the fact they were going to recall him and stress makes him ill. And he deteriorated after that and I did actually say to them you made him ill. You made him ill because you had those two meetings where one; you tried to bully him and the second where you were just rude and aggressive (611-615)

An emergency review under the Care Programme Approach (CPA) was held when Penny's son had a positive test result for cannabis while conditionally discharged. At that meeting the team questioned his denial that he had used the drug, which Penny perceived as 'bullying'. She blamed her son's deteriorating mental health on their treatment of him. Later in her account she acknowledged that he had taken cannabis, but her comment indicates that she attached blame to the team rather than her son's actions.

Once the blaming process has been activated this can lead to a breakdown in trust between parents and the team that is pervasive:

Laura: I'm never, never ever going to listen to anyone again. I'm gonna do what's in my heart to do. Because that is the only time that I listened to people and that, all turned out that Peter hung himself that weekend (488-490)

Laura had been advised by mental health professionals not to visit her son prior to his recall to hospital; advice she followed despite going against her “natural” inclinations. The content and vehemence with which she speaks indicates that her experience was so difficult that not only did she blame the team for advising her in this way, but her trust in the team completely broke down; this distrust has generalised to others.

5.3 An impenetrable system

This superordinate theme “an impenetrable system” describes parents’ experiences of desperately trying to get help for their son during conditional discharge from a service that appears not to be listening. There is a sense that they are banging on a shut door. Once their son has been recalled, the picture is of a service that then engulfs him so that parents feel excluded; and powerless in trying to get him out again. It appears that what enables parents to cope through their son’s conditional discharge and recall is finding someone who will be prepared to offer an open door to them.

5.3.1 Shut door

Having noted how impenetrable the system was when initially trying to get help for their son, parents described a similar experience during their son’s conditional discharge. Although when their son was first admitted they were grappling with an unknown system often felt as alien, they now had some knowledge of it because of their previous experience. Nevertheless despite this experience it seemed that

nothing had changed and they were still struggling to gain access to this seemingly impenetrable system. This cyclical process was best illustrated by Penny who had desperately but ineffectually tried to engage mental health services prior to her son's index offence:

I thought no, we're not doing this again; we're not going through this again; I didn't get it wrong the first time, nobody would listen to us and I didn't get it wrong the second time (734-736)

Her comment was in response to professionals' claim that she had not sought help when her son was deteriorating when conditionally discharged. There was a sense of frustration that just as she had struggled to get help for her son prior to his index offence, she had again been unable to get the team to take notice of her when he was becoming unwell again.

Across narratives there was a sense that parents were trying to gain access to a system from which they effectively felt shut out during their son's conditional discharge. They described processes by which the system excluded them; being ignored, dismissed, not taken seriously, or just no one available for them to speak to:

Clare: I'd told them [he was deteriorating] but they weren't taking any notice (635-636)

Clare felt shut out of the system because professionals ignored her. This led to her feeling blocked and resulted in her son not being properly looked after:

I felt he was completely let down by the people who were supposed to be looking after him, and I wasn't getting anywhere, telling them (459-460)

Although she was trying to get the system to take notice of her concerns about her son, she felt her efforts were constantly thwarted. Even when they did listen to her, she felt that they did not attribute any weight to what she had to say:

I spent six months at least [...] telling the people who were supposed to be supervising him that he wasn't; that 'he's not taking his medication, I know he's not, I just know it'. And they 'well, we can't do anything, you know, until we have the proof'. I said 'but, you know, I know he's not taking it, I know he's not well' (196-200)

Like Penny, Clare expressed a sense of frustration that she could not access help for her son. She clearly did not give up trying; she reported trying for at least six months, but her comment indicated that the door to such help for him remained firmly shut.

For some, the system appeared impenetrable through lack of availability; there was just no one available to whom they could talk. Laura described how the lack of staff and services meant that it was not possible for her to get a quick response to having found that her son had not taken his medication:

Laura: from Sunday, from finding the tablets, you can't get hold of anyone. So Monday, all day long, I'm phoning up social workers; nobody; can't get hold of anybody (...) nobody at all (417-419)

She gave an impression of desperately but ineffectually trying to reach anyone who could do something to help.

Having already spoken of the terrible struggle they had to get mental health services to respond to their concerns until their son committed an offence, parents highlighted a parallel process of things having to significantly deteriorate before they could get anyone to listen to their concerns about their son's mental state during conditional discharge. Clare put her personal concerns about the impact of professionals not listening into the context of national concerns and national systems:

Clare: why does it have to get so bad before anybody'll do anything? Why did he have to get, he was as bad as he was at 17 before anybody would do anything and then it's a much, much longer trek back [...] it's just not cost effective is it? I mean how much better for him, and for the nation's finances, and for us. I mean they know there's a problem with Michael, and if that could only just be caught (577-584)

There was a sense of how illogical and bewildering Clare felt the lack of response to her concerns about her son was. Not only was there a great personal cost to him when recalled to hospital in terms of the climb back to mental health, and to her when her son was again unwell; but there was a significant financial cost to the country in terms of the cost of keeping someone in a secure forensic hospital. She could not see why preventative measures could not be taken by mental health services rather than waiting until a crisis to react.

5.3.2 Engulfed

Once detained in hospital, restricted patients can only be discharged by a Mental Health Review Tribunal or the Secretary of State, and can be granted leave only with the Secretary of State's approval. Even when conditionally discharged into the community, they remain subject to the constraints of the conditions of discharge.

Parents understood that their son remained within the auspices of the Ministry of Justice. Nevertheless, their accounts of his recall described more than just a monitoring and treating system, but one where they felt their son had been ingested by and now belonged to the system. This is best illustrated by Trevor:

It's almost as if the patient is theirs, you can come and visit them, that's it (674-675)

He felt that his son belonged to the system, and that his only access was when he was permitted to visit. He saw that remaining in the system had its own dangers:

You do run the threat of being institutionalised if you're kept there long enough. And I hope, I really, really hope that John hasn't become so institutionalised that he won't be able to exist outside of there (133-136)

Trevor perceived remaining in this world as dangerous; a 'threat'; he wondered whether his son would become so used to living in this world, that it would destroy his ability to return to the real world.

There was a sense that their sons had been engulfed; swallowed up into an alien world, a world which could not be understood or comprehended; a world within a world. This world appeared to have generated its own rules and language which made it difficult for parents to understand how it operated from any 'normal' world, or logical perspective. While parents previously experienced not being listened to, this different language made it difficult for mutual understanding when communication did occur, illustrated by Brian:

We don't have open communication with them because [...] actually we don't seem to have the same language as them (623-625)

Not having a common language with professionals in the system meant that communication was hampered. Not only that, but he could not understand the rules by which system seemed to operate; the inequity and imbalance were perceived as unfair and illogical:

I never realised how [...] difficult it was to get somebody out of the system when we found it so hard to get him into the system. Seems so strange, that it took 90% illness to get him in, and it takes a perfection illness, or a lack of illness to get him out. They've got to be 90% unwell to get in; and they've got to be almost perfectly well, almost to the point that I don't even think most people get through that category; of so well to get out. It doesn't seem logical (547-555)

His experience led him to recognise potential outcomes of the system's functioning even if he could not understand its rationale. Brian's comment highlighted the illogicality of a system which was so hard to access, but then seemed to set impossible standards which needed to be reached before allowing its inhabitants back into a world where most people could not fulfil those exacting requirements. Although the rules appeared illogical to him, he understood the consequences of his son not meeting the requirements and realised that as a parent he was powerless in such an incomprehensible world:

We were asking for him to come out because he's well enough that he should probably get out again, but we knew the system and we went totally unexpected, well he didn't get out (645-646)

Parents found it difficult to understand what function the system was serving. For example Clare highlighted that one of the things her son had learned from his recall to hospital was that he had to conform to what the system expected from him. Deviance from what was acceptable to the system would mean another lengthy admission. There was a sense that working through the system entailed being shaped by the system into something acceptable to the people within.

Clare: Michael has learned a lot from that, not least he's learned that he has to toe the line otherwise other people have the power to recall him, and it's the work of a moment to be recalled, and it's a couple of years at best to work your way through the system and get out again (763-766)

Parents were confused as to why their son remained detained when apparently well. For example Brian thought his son was well, and no longer required detention in hospital. If he did not need continued treatment, the only reason Brian could see for this continued admission was for punishment.

Brian: we sometimes still think what they're keeping him long; as a sort of punishment, not because actually he's medically better kept in longer (219-220)

Penny's experience of the system was that it was inflexible, not adapting to the needs of the individual:

So they're saying "Oh well cos he didn't go through the systems and it's this one system must fit everybody", it's rubbish [...] and they're saying "Oh well he got unwell again because he didn't go through our system so this time we're going to put him through the system" (858-863)

Seeing the system as not fitting her son led Penny to dismiss it as 'rubbish'. She felt that the team wanted him to be processed through their system before they would regard him as suitable for discharge. It seemed that parents' experience of the system as rigid and inflexible may have had an effect of limiting their own ability to think flexibly:

Penny: he could have been a revolving door patient and all the rest of it. But he is actually now stuck in a system (250-251)

Penny described a dilemma where she could only see two outcomes for her son, whereby he was either in motion; a 'revolving door' patient; or 'stuck' in the system. Her account gave the impression that the inflexibility of the system restricted her capacity to perceive the circumstances in any other way.

Across narratives parents struggled to understand why their son was detained in the system for so long, having been recalled. There was a sense that getting someone out of this system required external assistance:

Brian: where he got out the first time with the Tribunal, he failed to get out with his Tribunal this time. We almost feel that it needs to be a Tribunal to get him out because we never felt the team are going to say he's ready to come out (858-860)

Embedded in Brian's account is the impression that the Tribunal is an operational body from the outside world, which has the power to rescue his son; 'get him out'.

Parents' narratives highlighted strategies the system adopts to ensure their son is retained. Brian indicated that he thought professionals deliberately portrayed his son in a negative light:

They weren't backing him coming out this time, so when they are not backing him coming out, they pile on the negativity. They bring up everything from the past; they can go back as far as they like; not just this readmission problems, but they go right back the beginning, and they paint such a black picture, I'm not surprised any board would actually let him out (648-651)

He described professionals choosing to paint a negative picture of his son after he had been recalled, reporting all negative historical information they may have, at the Tribunal which would be deciding whether or not he would be discharged. Brian felt the inherent unfairness of this but his account conveyed a sense of resignation and inevitability that his son would remain in the system.

Professionals were not only criticised for painting a negative picture, but for distorting the facts:

Penny: I think well, if in order to, to um, get what you want you have to distort the facts and sort of almost lie, it makes me angry. Because you should either be telling the truth and then giving it to the, the judge and the Tribunal to say well what do you think; and if you can't get what you want by telling the truth and at least putting it in the truthful light, then if the judge then turns round and says well he's obviously well enough to go home, well, he obviously Was well enough to go home (851-855)

Penny was angered by her perception that the system distorted the truth in order to keep her son detained. There is irony that a system which detains people because of

mental illness, one symptom of which is delusional or distorted thinking; was itself viewed as using distortion.

5.3.3 Open door

When facing difficulties and unable to gain adequate help and support particularly during their son's conditional discharge, parents cope by finding a door that is psychologically and sometimes physically open to them. These 'doors' are often outside of the system which is managing their sons. Multiple sources of support could or should be available for multiple concerns. They include family, friends, religious groups, and charities for example.

For Clare, emotional support appeared to come from talking to others:

Clare: Well I certainly talked to friends yes, and they were all supportive and sympathetic (298)

When she found she received no support from the team during her son's conditional discharge Clare found an outlet in her friends, people she could talk to who did listen and support her. Laura found her support came from her family:

I used to phone her [sister] and say do you know what he's done now? Cos she used to laugh and make a joke of it and that was my release valve you know (282-283)

She found that her sister could make her laugh, releasing her pent up emotion which was an internal pressure. Laura also used agencies specifically offering support to people:

I phoned up the Samaritans so many times. You know, just for me [...] they were helpful. They were very helpful you know, I just, I just talked to 'em. You know, cos I was so er, (...) well I was disturbed myself I suppose, when you think about it. You know, trying to cope with it all and get through it all (579-586)

Her account indicated that she needed help and support not just regarding her son, but to manage the collateral damage that she had sustained from trying to cope with the whole situation.

Sometimes what was needed was not talking, but just knowing someone else was there:

Brian: we're members of the local church round the corner and we've got some close friends in that and they'd, you know they knew that, they'd said an open house; I used to turn up to their house at five in the morning sometimes, make myself a cup of tea and, but that, that was necessary, it really was, you know, just to have people who were there (290-293)

Laura: very good, my neighbours, no, very, very good. They all know [...] they all know me, they all sympathise, very caring, you know, I'd only have to scream out 'help', you know, and somebody would be here to help me (694-697)

Both Laura and Brian appreciated the knowledge that people were there for them if they needed. There was a sense that they managed better knowing that there was a safety net should they need it. It was the availability of others; the open door, which made them feel safe.

5.4 The expert system

This superordinate theme “the expert system” reflects the experience of the parent who has a lifetime of knowledge of their son, giving him up to an ‘expert’ system which then assumes the monopoly of truth. Both during the conditional discharge and recall phases they express frustration and anger at being ignored or marginalised. Not feeling part of the team, there is a sense that parents feel alienated from mental health professionals, which can lead to a polarisation; with parents feeling as if they have to ‘take sides’.

5.4.1 Professionals’ assumed expertise

Parents felt that they have a deep knowledge of their son from the parenting relationship. Professionals have different knowledge about mental health. Both sources of expertise are important, yet there is a sense that parents feel that professionals do not value their personal knowledge.

Parents did clearly respect professionals’ expertise regarding mental health:

Clare: But when it came down to it we have to do what’s best for your child and (...) if the best thing for him was to be there, then that’s what I had to support. I’ve always said to him, you know, that these are medical decisions, and you know, I can’t, I’m not medical (287-289)

Seeing her son’s difficulties as medical, after her son had been recalled Clare deferred to medical professionals without any suggestion that she may have had

other views. Parents' accounts indicated that this respect was not always reciprocated:

Nobody, nobody took what I was saying seriously. And I think that's still a theme actually (57-58)

Clare described voicing her concerns about her son's behaviour before he was admitted and when conditionally discharged, but these were dismissed by mental health professionals. Later in the transcript she specified instances when she again expressed her concerns to professionals but was not taken seriously prior to her son's conditional discharge:

That was my worry, that he would not take his medication. And that the whole thing would backslide, which is what ultimately happened. And I voiced that frequently. And I was told absolutely, categorically, this could not happen. He was going to be supervised. 'We will know if he doesn't take his medication', but [...] it didn't work out (189-196)

I've always gone to his review meetings and been involved (...) but [...] just like when he was a teenager, I'm not the professional, so I don't know (252-254)

She was told that her worries were unfounded, and that professionals would know if her son was non-compliant with medication as she feared when he was conditionally discharged. She felt that because she was unqualified, the team assumed she had nothing to offer; her knowledge of her son was undermined, and her concerns dismissed.

When parents' knowledge was disregarded, this could affect how much they trusted the expertise of professionals. Knowing his son intimately meant that Brian was able to notice subtle signs of his son's mental state that he thought professionals missed; leading to an inaccurate assessment after his son had been recalled:

Brian: we have a better feeling of where he is than a medical person seeing him, assessing him, who get all the wrong signs. And they, they assess him wrongly completely, often they only get the wrong things (636-638)

Parents felt that their understanding of their son could help the team work with him. For example Penny recounted an incident after her son had been recalled when the team wanted her son to have a brain scan and she realised that he thought they were suggesting electro-convulsive therapy. She tried to explain the misunderstanding to him because she knew from experience what his response would be if he felt pressurised to do something he did not want to do. She had the sense that even though she knew what had happened during the transaction, the team still dismissed this, thinking that they should know:

Penny: I know my son; you've got to introduce something; let him think about it and then come back to it; it's no good trying to bully him, all that happens is actually that he will dig his heels in [...]. And that's exactly what happened [...] if you'd only backed off when I asked you to back off, and let me explain to him [...] And of course he just dug his heels in and went 'No'. And afterwards it was like they were all sitting back thinking (...) what just happened then? (577-591)

Following their son's conditional discharge, parents often have a high level of contact with him. They are therefore ideally placed to be part of the monitoring process. However parents reported not being asked for feedback:

Trevor: I wasn't asked to give any feedback at all (695-696)

That Trevor was not asked for any feedback about his son by the team highlighted the lack of value the team placed on his knowledge of his son. It appeared that this knowledge was totally excluded by professionals.

Sometimes parents made their views known whether or not these were sought by the team:

Laura: It's the first time in my life that I've put my foot down with somebody [...] but I put my foot down and I said 'Peter Isn't going to this [discharge placement]. [...] I said 'I don't care', I said 'you can tell me there's no places elsewhere', I said 'there's X, that's where I want him to go (534-542)

As parents gained experience of the mental health system, there was a sense that they became more confident in their challenges and were not prepared to be sidelined. When the team planned her son's discharge, Laura thought that the placement which had been identified for when her son was again conditionally discharged was unsuitable and was not prepared for her views to be ignored.

5.4.2 Not treated as equals, not part of the team

Besides feeling that their knowledge of their son is undervalued, parents felt that they were not treated as equals by professionals both during their son's conditional discharge and recall. They saw the flaws in the system, and made negative comparisons between the service they expected and that which they received. The splitting that occurred led to some parents feeling as though they were pushed into taking sides with their son. Brian's comment illustrated his perception of the one sided nature of involvement with the team:

They expect us to be part of the team and tell them when he's getting problems; but they don't include us as part of the team (605-607)

He felt that the onus was on him and his wife to provide the team with information about their son, but this was not reciprocated.

Parents noted that professionals did act as if they were involving them as part of the team, but this was experienced as indifference rather than feeling engaged as valuable co-workers:

Clare: So frustrating, so frustrating, and I just, what's the point of involving me [...] come along to the meetings, Michael wants you there, but, you know (...) but when it came to listening to what I was saying, just really not interested (446-449)

Brian: We get a voice occasionally but we don't feel that it's really affecting anything (662-663)

Both Clare and Brian's comments (about their experience of their son's conditional discharge and recall respectively) suggested that although they were invited to be part of the team, they experienced this as a token gesture. Even when they were offered an opportunity to give their views, they felt as though their voice was unheard because it made no difference to anything involving their son.

Parents were effectively alienated through the team's inaction:

Brian: I know they can't give us a plan of what's going to happen, but they don't seem to give us anything (842)

Trevor: he was recalled [...] I didn't know anything until, until he was back in the [medium secure unit] (260-263)

Brian accepted that the team was unable to give him definite answers as to his son's future once his son had been recalled, however his experience was of an apparent power imbalance which made it possible for the team to be withholding. Trevor indicated a complete lack of communication from the team during his son's conditional discharge, even regarding his son's recall to hospital.

Alienation was exacerbated through parents feeling disrespected by professionals:

Penny: I mind the fact that somehow we're being treated as second class citizens. If you're having a meeting that goes on for an hour, then we all have coffee and biscuits. If you don't want to give me coffee and biscuits, then you don't have them either (801-803)

Penny experienced the team as perceiving her to be inferior after her son had been recalled. Throughout her account she emphasised her professional role as a teacher, expecting to be treated as a professional. She felt like an outsider; the coffee and biscuits symbolic of the privilege afforded to those inside the group. Refreshments were available for the mental health professionals, but she had not been offered any.

Not part of the team, parents felt as though they were seen as a problem:

Penny: I think they consider us a nuisance (812)

Clare: the attitude from the outreach team there, was, you know, this really isn't your business, Michael is an adult and we are his support workers, and yes you're his mother and obviously you're concerned but it really isn't your business, you know, we know what we're doing and go away [...] they were tolerating me and I was a bit of a nuisance, but really [...] not seen as a resource (609-623)

Both Penny and Clare felt the team regarded them as a 'nuisance', Penny when her son had been recalled, Clare during his conditional discharge. Clare elaborated on this; now that her son was an adult, the team thought that his situation was nothing to do with her. She had the impression that they felt that she was irrelevant and that they would have preferred her to have no contact with them.

Their experience appeared to push some parents into taking sides:

Brian: he seemed to have, quite often have a CPA meeting [...] Nobody seemed to come round this side and actually sit [son]'s side and argue it, which ends up falling

on us which at times is a real pain because it means that we end up on the wrong side as well. So we can't work with them [...] Very polarised (828-837)

Brian's experience was that the hospital team never attempted to see things from his son's perspective after his son had been recalled. In trying to balance this, he felt he was pushed into siding with his son, but acknowledged that this meant he was sometimes on the 'wrong' side. The result was a breakdown in any possibility of working collaboratively with the team. His use of the word 'polarised' indicated the extreme gulf he felt existed between him and the team.

6. Discussion

This chapter offers a short summary of the study, including the results. The issues relating to this specific population will be highlighted and different themes considered in the light of the extant literature. Implications of the study for both clinical practice and future research will be commented on. The study will be evaluated in terms of methodology with a discussion of the limitations inherent in the study. The chapter concludes with my reflections on the research process.

The purpose of this study was to explore the experience of parents of sons who have been conditionally discharged from a forensic medium secure hospital and subsequently recalled to hospital under s37/41. Participants provided rich and detailed narratives, which were transcribed verbatim and subjected to systemic analysis through the lens of Interpretive Phenomenological Analysis (IPA) (Smith & Osborn, 2008). Four super-ordinate themes were generated from the participants' accounts relating to: 1) emotional impact; 2) responsibility; 3) an impenetrable system; and 4) the expert system.

6.1 Issues relating to the specific forensic population.

As outlined in the introduction, the majority of research into the impact of having a family member diagnosed with mental illness has attempted to quantify the impact of caring for that person. Although there has been some qualitative research into the experience of families associated with having a family member diagnosed with mental illness, both in the community and hospitalised within general psychiatric

services, there has been a paucity of research into the impact of having a family member detained within forensic services. As with studies focusing on the general psychiatric population, research into the experience of parents within the forensic arena has mainly focused on the burden experienced by carers. It has been argued that such an approach does not acknowledge the complexities of this phenomenon for the individual. Moreover there are a number of issues that pertain to this specific population which need to be borne in mind when thinking about the themes that resulted from the analysis in this study.

Mezey and Eastman (2009) have pointed out that there is a tension between the government's commitment to choice, empowerment and social inclusion, and 'its equally committed stance with regard to public protection within an increasingly risk-averse society' (p503). Holloway (2007) notes that any preference of the patient will be subjugated to the imperative to manage risk where the two are in conflict. Eastman (2006) parallels this tension as between the clinician treating the mental health and the Home office with its focus on public protection; offering a metaphor of the 'Home Office as the disciplinarian father and the clinician as the caring mother' (p460). It is perhaps unsurprising if parents of patients in this specific forensic population pick up on this inherent tension. Given that the role of the Home Office is to promote public protection, the liability of the restricted patient to recall indicates that the imposition of the restriction order is primarily for this purpose. Brown and Fahy (2009) highlight the significantly longer admission periods for patients detained under s37/41 than those detained under a civil section. They suggest that the restricted population have been convicted of more serious criminal acts and present a higher level of complexity and risk. However, they also suggest that the caution of

the Ministry of Justice regarding discharge may mean that restricted patients are more likely to be discharged to supported, rather than independent, accommodation. This in turn can slow down the process of discharge, as hostels may prefer referrals of non-forensic patients. Parents of this specific forensic population may find it difficult to understand why their son remains in hospital when he appears mentally well, or why it takes so long to achieve leave, permission for which also rests with the Home Office.

Other issues relating to the specific forensic population are varied, some of which may relate more to the preadmission or earlier stage of admission rather than conditional discharge and recall. Those relating to the earlier stages may include the family being the victim of the patient's violent offending, which may result in ambivalence among families regarding the perpetrator (James, 1996); coping with the Criminal Justice System (Tsang et al., 2002; McCann et al., 1996); coping with serious offending behaviour (McCann et al., 1996); and coping with the media (Tsang et al., 2002; James, 1996).

Parents may be affected by the greater distance involved in visiting their son as forensic services tend to cover a greater catchment area than local psychiatric services. This can affect them in both the admission and recall phases, adding to the practical demands of maintaining contact with their son (McCann et al., 1996). In a study conducted by Absalom-Hornby et al., (2011), mental health professionals highlighted this factor as a barrier to successful implementation of family therapy in forensic services.

When their son is conditionally discharged, he may be transferred to the care of local services, although this is not invariably so. It is recognised that forensic services are better resourced than the community (Naylor & Bell, 2010; Sainsbury centre, 2009; Coid et al., 2001), which may mean that transfer to local services results in their son receiving a comparably impoverished service, which parents can perceive as inadequate support. A further factor specific to the forensic population is that discharge from hospital is subject to conditions, which can be viewed ranging from protective and containing to restrictive and limiting of autonomy. The conditionally discharged patient remains constantly liable for recall, with the additional feature that recall does not require a relapse in mental state. Recall would then re-institute the full force of the hospital order with restrictions.

Although these are important aspects relating to the specific forensic population, to date there has been no published research investigating the experience of parents or sons who have been conditionally discharged and then recalled to hospital. Thus the themes highlighted in this exploratory study are discussed in the light of both the extant literature from the more general psychiatric population, and where possible, the literature relating to the forensic population. It should be recognised however that the literature relating to the forensic population is limited to preadmission and admission.

6.2 Present study in the light of previous findings:

6.2.1 Emotional impact

6.2.1.1 Hope and Reappraisal

In line with previous studies of both the general psychiatric population and a more specific forensic population, parents had expressed some relief when their son was finally admitted to hospital, (Ridley et al., 2010; Cormac & Tihanyi, 2006; Nordström et al., 2006). They hoped that he would progress; and an aspect of their experience specifically relating to the forensic population, generally viewed the restriction order positively, accepting that the conditions would offer some containment. There has been no previous research into the experience of parents whose sons have been conditionally discharged, but these parents reported complex feelings of pleasure, tinged with fear that he may not succeed in the community and be recalled. As they saw their son deteriorate, each parent described a process of reappraisal of their hopes and expectations which enabled them to regain a sense of hope once he had been recalled. In a study relating to the forensic population, Nordström et al. (2006) note the lowering of expectations that parents have for their son as time progresses, initially wanting him to return to his premorbid level of functioning, later hoping for much less. However, this reflected studies in the general psychiatric population such as Bland and Darlington's study, (2002) which found that the hope held by families was threatened when their relative was ill, and bolstered in times of recovery. Hall et al. (2008) agrees that hope is dynamic, and connected with the individual's potential. Researchers have highlighted processes of adaptation that occur when a relative's mental state deteriorates (Wynaden, 2007; Schene, 1990). The cognitive adaptation

theory (Taylor, 1983) suggests that people adapt to regain mastery and control following a threatening event by searching for meaning, both to understand why the event occurred, and to assess its implications for life now. It could be argued that for parents of sons with a restriction order, any deterioration in his mental state could signify greater potential losses; potential reoffending, and / or a further potentially lengthy admission. To regain hope would then entail a high level of adaptation and reappraisal. Parents in this study searched for meaning for their son's deterioration; when the attributed cause was no longer present (for example when he was no longer using illicit substances or was now compliant with medication), this could engender renewed hope. Parents also described lowering expectations of their son. Re-ordering their priorities may also have assisted parents regain a sense of mastery and hope, as their son was more likely to achieve these lowered expectations. Parents distinguished between what they saw as normal for their son, and deterioration in his mental state. This finding is consistent with findings in the more general psychiatric population such as Rose et al. (2002), who found that adaptation leads to a redefinition of what can be expected.

6.2.1.2 Fear and Loss

The cyclic pattern of loss and hope noted by researchers investigating the general psychiatric population (Lefley, 1989; Bland & Darlington, 2002) was experienced by parents in this study. Parents of sons in this specific forensic restricted population, reported worrying about whether their son would manage in the community and act in ways that would promote his own wellbeing. They described feeling scared due to lack of trust in both their son and in the supervision he would receive, and worried

that he would be recalled. Given the nature of the risks associated with any deterioration in his mental state, both to others and in terms of his future within the community, this fear is understandable. Other studies of parents of the mentally ill have found that many worry about their child's future both in the general psychiatric population (Rose et al., 2006), and the forensic population (Tsang et al., 2002). Similar to other families (Drapalski et al., 2009), parents of sons in this specific forensic population expressed fear for their son's safety as well as potential relapse. Knowing his history of violence, they were well aware of the potential for violence, and his deterioration caused them extreme fear. Parents avoided the prospect of their son's deterioration by hoping that it was a unique incident and denying that it was the beginning of a process of deterioration.

Denial can protect people against crises, particularly in the initial stages of threat (Taylor, 1983) and many authors have suggested that denial is part of the cycle of grief and loss, similar to bereavement (Penzo & Harvey, 2008; Bruce & Schultz, 2001). Feelings of grief and loss have been articulated by parents of patients diagnosed with schizophrenia in a forensic setting (Ferriter & Huband, 2003) as in the current study. It is not clear whether there is a different quality of grief among parents of sons detained within forensic services compared with those in the more general psychiatric population. Nevertheless aspects of grief as reported in the general literature are reflected in the accounts of parents within this study. Grief and loss as reported in the general psychiatric literature suggests that grief can be prolonged (Rose et al., 2006; Goddres et al., 2005; Winefield et al., 1998) as parents come to accept the loss of their son's premorbid personality (Lefley, 1989), and mourn their hopes and aspirations for him (Wynaden, 2007; Nordström et al.,

2006; Foldemo et al., 2005; Milliken & Rodney, 2003; Osborne & Coyle, 2002). However this grief is “non-finite” (Bruce & Schultz, 2001, p6.) as there is no clear lost object, and they continue to have a relationship with their son (Ozgul, 2004). They are therefore disenfranchised from expressing their grief as their loss is not socially recognised (MacGregor, 1994). Bruce and Schultz (2001) highlight the relentless nature of non-finite loss. Acknowledging the idiosyncratic nature of grieving they note common cycles of grief, with themes of shock, protest, defiance, resignation and despair, followed by integration. They suggest that these patterns are prone to recycling with an underlying thrust towards integration. The experience of parents of the specific forensic population in this study seemed to reflect this cycle: shock represented by denial of deterioration; protest in challenging their son; defiance, trying to make things right; resignation and despair (parents described feeling powerless to halt their son’s deterioration); and integration through the process of adaptation already discussed.

6.2.1.3 Identity

Parents in this study of a specific forensic population felt that they were defined by professionals in terms of their son’s identity as a mentally disordered offender rather than as an individual. Several parents felt they were regarded as a nuisance. Buber (1937/2010) described an I-Thou relationship where people recognise the full humanity of the other, as opposed to an I-it relationship, where the other is seen only in terms of a limited aspect. It is understandable that professionals relate to parents in terms of their son, but this should not preclude seeing parents as individuals with their own needs and expertise. Indeed Government policy has proposed that carers

be recognised and supported to have lives outside of this role (Department of Health, 2008a). Nevertheless, while parents were often left responsible for their son when he was conditionally discharged; when he was recalled, they felt disenfranchised even in this role. This finding agrees with that of Milliken and Rodney (2003), who found that parents of mentally ill adult children in the general psychiatric population “periodically revise their role and identity during their child’s illness trajectory” (p759). In this study of parents of sons detained within the forensic system, many vehemently opposed viewing their son as an offender. In the more general psychiatric population parents can find their son’s hospitalisation as highly stigmatising (Phelan et al., 1998), whereas this is compounded by the addition of the forensic tag (Absalom et al., 2010). Nordström et al. (2006) also found that it was important to parents that their son was not regarded as an offender but someone with a mental disorder. In line with this research into the forensic population, the current study suggests that it is the forensic rather than the psychiatric label that is potentially most stigmatising to parents. Goffman (1963) proposed that people experience vicarious or ‘courtesy’ stigma through their association with a person marked by stigma. In resisting this notion of their son as a mentally disordered offender, parents may well be challenging their own identity as perceived by professionals, who “should be aware of the potentially stigmatising effects of their own practice” (Schulze, 2007, p139).

6.2.2 Responsibility

6.2.2.1 Parental responsibility

Parents described a high level of commitment to their son, supporting him practically and emotionally. This is consistent with the literature in the general psychiatric population which confirms that it is most often parents who care for their adult children suffering from severe mental illness (Absalom et al., 2010; Ridley et al., 2010; Drapalski et al., 2009; Milliken & Rodney, 2003; Bulger et al., 1993), and that this is beyond what would normally be expected in the lifecycle (Schene et al., 1998; Lefley, 1997).

In this study within a specific forensic population, parents wanted to try to 'put things right' when their son's mental health began to deteriorate. Consistent with other studies in the general psychiatric population (Ozgul, 2004), parents described a feeling of powerlessness when they realised that they were unable to halt their son's deterioration, which led to a process of resignation. Recognising that he needed a higher level of care than they could provide, but not wanting him to lose his independence and freedom, they experienced a dilemma as to whether they should seek recall. Milliken and Rodney (2003) note that parents in the general psychiatric population face a moral struggle about what they ought to do for their child when there are competing claims such as their child's independence and need for a safe environment. Parents are constrained in their choices when no preferred option is available to them. This reflects the conflict that parents have in seeking hospitalisation when there is no other option available to keep their child safe (Lefley,

1997), but within this specific forensic population knowing that recall reactivates the full weight of the restriction order may be a worse dilemma for parents. Milliken and Rodney (2003) point out that the unresolved moral distress resulting from this moral struggle can exhaust parents' ability to act as moral agents.

6.2.2.2 Autonomy vs. Infantilisation

Autonomy is invariably compromised for restricted patients within forensic services. Sen et al. (2012) suggest that as the courts recognise that mentally disordered offenders have less responsibility than criminals with no mental disorder, the principle of autonomy within medical ethics is 'less relevant in forensic psychiatry compared with other medical disciplines' (p340). They question how far autonomy is possible when patients are 'compulsorily detained and the healthcare professionals perceived to be (and to some extent are) controlling and coercive' (p338). The restriction order limits their capacity to exercise choice over their treatment; management decisions are highly influenced by managing risk to the public; and a prolonged admission in medium security can result in passivity, making it difficult to 'promote self-care, independence and autonomy' (Mezey et al., 2010, p684). By implication, the restriction order in hospital and conditions of discharge in the community mean that the patient is subject to a higher legal authority. Autonomy could therefore be described as an ideal which cannot be fully reached for this specific forensic population. The results from this study into the experience of sons within the forensic psychiatric system reflects those found in studies into experience of parents and families in the more general psychiatric population discussed below. In this (forensic) study parents described a level of care and support for their son,

beyond which they might normally have expected to provide if he had not been mentally ill (Schene et al., 1998). They take responsibility for him into adulthood, recognising that he may never achieve the independence they anticipated. Research highlights that along with many professionals, the media believe that people with mental illness cannot be cured (Wahl & Aroesty-Cohen, 2010; Schulze, 2007), a view which is also held by parents of patients in the general psychiatric population who are more pessimistic than patients regarding their recovery (Kuipers et al., 2007); believe that they require close supervision (Small et al., 2010); and consequently remove responsibilities from them (Tsang et al., 2002). Some professionals believe that families hinder their relative's recovery by their paternalistic attitude (Nicholls & Pernice, 2009), while other authors have commented that it is the mental health system which infantilises the patient, giving the message that they are incapable of adult behaviour (Lefley, 1997). It could be argued that for patients within the restricted forensic population, this infantilisation by the system is even more marked because of the control exerted by the Ministry of Justice. By implication, it is possible that parents of restricted patients may receive the message that their son is incapable of adult behaviour and thus mirror the infantilisation process. Parents described wanting their son to be independent but evidence of his deterioration and a lack of response from mental health services led to their recognition that he may always require their support, consistent with previous findings in the general psychiatric population (Wane et al., 2009; Hanson, 1993). While parents of non-mentally ill adult children have some difficulty in allowing them to gain independence (Kloep & Hendry, 2010), this may be particularly hard for parents of forensic patients who have little capacity to exert choice and control, and

spend prolonged periods in secure care which mitigates against autonomy (Mezey et al., 2010).

6.2.2.3 Uncertainty as to who is responsible

Uncertainty is a common experience across chronic or relapsing illnesses (Greenwood et al., 2009; Stone & Jones, 2009; De Graves & Aranda, 2008; Brashers et al., 2003), and characterises the experiences of families of the mentally ill in the general psychiatric population (Lefley, 1997). Uncertainty can be unpleasant and may intensify affective reactions to emotional events (Sorrentino et al., 2009). One source of uncertainty for parents of the mentally ill in the general psychiatric population is associated with service delivery (Rapport et al., 2010). Studies have found that sharing responsibility for their son with professionals can be reassuring for parents in the general psychiatric population (Wane et al., 2009) and within a forensic population on admission (Nordström et al., 2006). Parents in the current study of a specific forensic population described feeling isolated and unsupported, particularly during their son's conditional discharge. Parents of conditionally discharged patients, where the supervising team is accountable to the Ministry of Justice, could reasonably expect a high level of support and sharing of responsibility with the team. Parents interviewed for this study described how they had been assured of this, and expressed frustration and anger when it did not materialise. Lefley (1989) also found families in the general psychiatric population were frustrated when met with ambiguous communications from team. Feeling isolated and unsupported parents in the current study were not even encouraged in the support they were providing, echoed by participants in a study of the general psychiatric

population by Winefield et al., (1998). A common theme in the general psychiatric literature and described by parents in this forensic study is not knowing who to contact (Carter, 2011). Research suggests that the importance of this has been underestimated by mental health services (Wane et al., 2009), and parents in both the current forensic study and others in the general psychiatric population (Cormac & Tihanyi, 2006; Winefield et al., 1998) have suggested that they need an identified, accessible and responsive person to alleviate feelings of isolation and helplessness.

6.2.2.4 Blaming and feeling blamed

When their son's mental health deteriorated, parents in this study of a specific forensic population reported feeling blamed by professionals. Other studies in the general psychiatric population have confirmed that parents experience blame during the course of their son's illness (Nicholls & Pernice, 2009; Corrigan & Miller, 2004; Milliken & Rodney, 2003). The literature suggests that this blame may result from professionals' residual beliefs about family pathology involved in the aetiology of mental illness, despite such models being largely dismissed (Ferriter & Huband, 2003; Chaplin, 2000). MacInnes (2000) suggests that parents of patients in forensic services are further stigmatised by their son's offending, and it may be that parents in this situation may already have heightened sensitivity to perceived criticism (Kuppens & Van Mechelen, 2007; Corrigan & Miller, 2004). Within a more general psychiatric population Hatfield and Lefley (1987) argue that even implicit blame only serves to accentuate parents' difficulties: they argue that in response to feeling criticised, professionals should provide emotional support rather than expressing or implying blame. Parents reciprocated by blaming professionals for not caring

properly for their sons. Lefley questions whether being blamed may evoke defensive strategies in family members that “reinforce the clinicians’ preconceptions of deviance” (Lefley, 1989, p.558). Moreover professionals feel that families in the general psychiatric population blame them for the patient’s poor prognosis (Nicholls & Pernice, 2009). Thus there is the possibility of a spiralling process of blame, where each party blames the other. Shaver and Drown (1986) developed a three-stage model of blame attribution, where the perpetrator’s actions are sequentially judged according to causality, moral responsibility, and evaluation of justification (Bell, 1989). According to this model, parents of sons detained in forensic services can excuse their son’s behaviour on the grounds of moral responsibility (he is ill), while blaming a system which is perceived to have failed him in the first place. Predisposition to blaming appears to be associated with a lack of a trusting relationship (Kuppens & Van Mechelen, 2007; Rosenthal & Schlesinger, 2002). For the blaming process to stop, effort needs to be put in on both sides to develop a mutually respectful and trusting relationship.

6.2.3 An impenetrable system

6.2.3.1 Shut door

Although parents in this specific forensic population had described being unable to get help for their son until a crisis had occurred and he committed the index offence, they also had difficulty in accessing help while he was conditionally discharged and thus well known to forensic mental health services. MacInnes (2000) also highlighted the poor service that parents perceived their child received from mental health

services before they seriously offended. Other studies in the general psychiatric population have highlighted struggles that many families have in trying to get services to take notice of their mentally ill member, even in an emergency situation (Carter, 2011; Gray et al., 2010; Askey et al., 2009; Wane et al., 2009; Wynaden, 2007). Although this situation is woeful, demand for resources go some way in explaining this lack of response. However, forensic restricted patients are well known to services, they have extensive documented risk assessments, and the conditions on discharge are there to ensure that any deterioration is picked up early (Home Office, 2007) because of the inherent risks associated with relapse, so it could be argued that they are a high priority for receipt of scarce resources. Hanson (1993) in his study of American families caring for a mentally ill relative in general psychiatric services found that despite their relative being known to services, they still felt isolated and unsupported in a crisis. It seems astounding that there is such a lack of response to parents' concerns within this specific forensic population.

6.2.3.2 Engulfed

Once patients were recalled to hospital, parents in this study of a specific forensic population described how difficult it was to 'get him out' again. Brown and Fahy (2009) noted that within secure forensic services, restricted patients were detained significantly longer than those detained under civil section, transferred from prison, or detained under a hospital order without restrictions. They suggested that the reasons for this could be: that restricted patients have been convicted of more serious offences and pose a higher level of complexity and risk; that caution exercised by the Ministry of Justice can slow their progress through the system; and

that accommodation providers may prefer non restricted patients. If families of patients detained under civil sections in the general psychiatric population are 'critical of what seemed to be unnecessarily protracted stays in hospital' (Ridley et al., 2010, p.478), it is perhaps unsurprising that parents of restricted patients within a specific forensic population who are detained for significantly longer periods, also expressed dissatisfaction with their son's length of admission.

Parents in the current study within a forensic setting described not having a common language with professionals which hindered effective communication with them, consistent with findings in the general psychiatric population in a study by Ridley et al. (2010). Drapalski et al. (2009) noted that people who do not have experience of the general psychiatric mental health system may need information to successfully navigate it. Despite their experience of the forensic mental health system, accrued over an extended period by the time their son had been conditionally discharged, parents still expressed difficulty in comprehending its operation and function. The sense of their son being owned by the system reflects the concept of a 'total institution' (Goffman, 1961) who described complete segregation from the outside world. This was perceived to be the case by many parents in this current study during their son's recall; even if not factually true.

Parents in this specific forensic population felt that the system had no flexibility in meeting the needs of their son, and that professionals distorted the facts when writing reports, which led to his continued detention beyond what they felt was required. The MHRT system was viewed by them as an agency which could override the system and discharge their son. Schulze (2007) has highlighted the perception in

the general psychiatric population of mental health services as offering the same treatment to everyone. She noted that mental health professionals have the power to define normality by setting goals for patients which may be unrealistic. The implication is that patients cannot be successfully rehabilitated if they cannot achieve these goals.

6.2.3.3 Open door

Parents in this study within a forensic setting have often had to draw on remarkable reserves of strength, resilience and support by the time their son was conditionally discharged. For the parents in this study, these reserves were also required after his conditional discharge. Sources of support included friends, family and other social networks, use of humour, their faith, and external agencies specifically set up to support people. This is consistent with previous research which has investigated which factors enable parents, families and carers to cope with having a family member with mental illness in the general psychiatric population. Social support may alleviate distress felt by relatives of mentally ill patients (Parabiaghi et al., 2007; Magliano et al., 2003), particularly when they feel undervalued by healthcare workers (Cormac & Tihanyi, 2006). Humour is often used by people to diffuse tense situations (Maiese, 2006) and can be a means of venting feelings and creating emotional distance from a difficult situation (Rowe & Regehr, 2010). Having a strong faith and the support of a religious network has been associated with increased well-being (Wynaden, 2007; Fortune et al., 2005; Bland & Darlington, 2002; Rammohan et al., 2002; Johnson, 2000). Cormac and Tihanyi (2006) suggest that the voluntary sector can also offer support and encouragement. Obtaining emotional support from

others may facilitate the reframing process and bring hope (Lakeman, 2008). Fortune et al. (2005) found that positive reframing reduced psychological distress in relatives of people with schizophrenia in the general psychiatric population. Although parents within this specific forensic population identified a variety of coping strategies, they acknowledged that they also resorted to avoidant strategies such as drinking excessively at times of extreme stress which exceeds their capacity to deal with situations, also found in the general psychiatric population by Chadda et al. (2007) and Raune et al. (2004).

6.2.4 The expert system

This study confirms previous findings in the general psychiatric population regarding the often difficult relationship between parents and mental health professionals. However, it adds to the current paucity of literature regarding parents' experiences within forensic services.

6.2.4.1 Professionals assume expertise

Parents' knowledge of their son can be extensive resulting from a lifetime of knowing him. This knowledge can be invaluable to professionals both in terms of learning about his history, the nuances of which cannot be contained in reports; and from a management perspective in terms of understanding his current presentation, and patterns of responding (Drapalski et al., 2009). Feedback from families who took part in a pilot project where families and ward staff in a general psychiatric hospital met together (Carter, 2011) indicated that they appreciated the opportunity to be able

to tell staff what their son was like before he became ill. It should be recognised that forensic psychiatrists are cognisant of the demands of the Ministry of Justice (Eastman, 2006) and there is an assumption that they may have to make decisions with which the patient and / or their parent may disagree. It may therefore seem to parents that professionals perceive their own expertise as superior, which can lead to distrust. In line with the current study within a specific forensic population, Nicholls and Pernice (2009) found that families in the general psychiatric population reported that their expertise and integrity were questioned by professionals, and that not being believed or consulted and being ignored led to feelings of powerlessness, frustration and anger. This finding is reflected in other studies in both general (Gray et al., 2010; Cormac & Tihanyi, 2006; Kaas et al., 2003; Chambers et al., 2001; Winefield et al., 1998) and forensic (Nordström et al., 2006) psychiatric settings. Penzo and Harvey (2008) suggested that both parents and professionals need to respect what each contributes to the understanding of the client. As Schulze (2007) comments, such sharing of power does not imply any decrease in the power of psychiatric expertise. It could be argued that for the forensic psychiatric population, the highest authority lies with the Ministry of Justice. Nevertheless, this does not diminish the importance of sharing of personal and professional expertise by parents and mental health professionals respectively. In the general psychiatric population it has been found that when professionals and families value each other's contribution this can enhance collaboration, which in turn increases the likelihood of positive outcomes for both the family caregiver and the ill family member (Wynaden et al., 2006). The accounts given by parents in this specific forensic population suggest that they desire a collaborative approach, and that they have a forum where they can share their expertise. Consistent with the findings in a general psychiatric population

by Winefield et al. (1998), parents in this forensic study described increased assertiveness in dealing with professionals as they gained experience of the mental health system. Thus they were able to challenge and question more during the recall phase of their son's admission than they had when he was first admitted.

6.2.4.2 Not treated as equals

Far from feeling part of the team, participants within this specific forensic population described a process of exclusion, whereby if they were acknowledged at all, they felt that this was a token gesture. This reflects the findings of previous research in the general psychiatric population (Askey et al., 2009). In common with participants in this study, Wynaden and Orb (2005) found that the lack of collaboration with health professionals left families of patients admitted to a general psychiatric hospital feeling resentful and frustrated. Wilkinson and McAndrew's (2008) phenomenological study highlighted that although carers of patients admitted to general psychiatric acute inpatient services wanted to work in partnership with healthcare professionals, this did not happen. Participants in their study thought that professionals viewed their wish to be involved as threatening their expertise.

One barrier to collaborative working with parents in the general psychiatric population that professionals have identified is professionals' time (Rose et al., 2004). There is increasing pressure on community resources, which can make working in partnership with parents invaluable. When their son is in the community, parents often spend more time with him than do professionals. They may therefore observe early warning signs of deterioration more quickly than professionals

(Nicholls & Pernice, 2009; Johnson, 2000). Within the specific forensic population under investigation in this study, parents described the supervising team as ignoring or dismissing their concerns. Macinnes and Watson (2002) found that forensic caregivers expressed annoyance with services, in terms of anger and frustration; and 'the perceived indifference (and at times outright hostility) to caregivers' concerns and experience' (p385). Similar findings are reflected in other studies both in the general (Doornbos, 2002) and forensic (Ferriter & Huband, 2003; McCann et al., 1996) populations. Although community teams within general psychiatry may have limited time to develop a collaborative relationship with parents, for those within forensic services, the usually lengthy prior admission to hospital offers an opportunity for parents and professionals to develop a positive working relationship. In the general psychiatric population, one exploration of what hindered collaborative practice indicated that professionals did not identify their own attitudes as a barrier, suggesting that professionals make no effort to see the situation from parents' perspectives (Kaas et al., 2003). However, Nicholls and Pernice (2009) found that professionals understood the benefits of a positive working relationship with families but were unsure as to how they could go about developing this. They highlighted barriers such as lack of skills and issues of confidentiality. Rose et al. (2004) noted that collaboration is difficult when families and health professionals have different notions of what is needed. However, in the study reported here for parents of sons within forensic services, parents clearly wanted their son to progress, a goal presumably held in common with mental health professionals.

6.3 Limitations

This section offers an account of the limitations of the study, together with the researcher's own reflexions regarding personal impact on the study and analysis.

Although this study has provided valuable information about the experience of parents of sons who have been conditionally discharged and then recalled to hospital under s37/41 the findings of this study must be evaluated in light of the methodological considerations examined below.

6.3.1 Methodology

IPA uses an idiographic approach, which is ideal for exploring the experience of individuals. In this study, two parents of the same son were interviewed. Although they each clearly had their own unique experience, there was some shared construction of their experience. It could be that the experience of the family unit does not precisely reflect the individual parental experience, and this could be the subject of further research.

6.3.2 Interview schedule

In order to gain rich data which did not limit the participant's account, the interview schedule was used as a guide rather than adhered to rigidly. It was hoped that the semi structured interview schedule allowed participants to offer accounts which aligned to their own focus rather than those predetermined by the researcher. One of

the main strengths of IPA is that it recognises the role of the researcher on the research process. Rather than deny or avoid the researcher's position, IPA relies on the researcher being as transparent as possible, noting any preconceptions, assumptions and, for example, keeping a reflexive diary. From the outset, asking the research question, designing the study, constructing the interview schedule, data collection, and analysis, IPA acknowledges that the researcher necessarily impacts on the research process.

The construction of the interview schedule has been described in paragraph 4.2.3.1. Questions in the schedule related to the thoughts, feelings, and impact of the admission, conditional discharge and recall of their son on the participant, both personally and relationally. Although these questions appear to be general in order not to lead the participant, it is possible that a different researcher might have generated different questions. A researcher with little or no experience of working in forensic services may have been distracted by parents' accounts of their son's index offence; or how forensic psychiatry fits into the criminal justice system; or what a forensic unit is like. A researcher new to mental health services may not realise how difficult it is to get services to respond; or they may not realise the limitations of community resources to liaise with families.

The literature had suggested that loss and grief was a major factor for parents of people with mental illness. I knew that I had a specific interest in this having worked as a volunteer bereavement counsellor. IPA relies on an open-minded investigation and I was very concerned that I did not presuppose the outcome of the study, or direct participants in this direction. I therefore did not want to ask specific questions

about loss and grief, or indeed about any specific positive or negative aspect of their experience. In retrospect, it may have been helpful to think about what questions I might have asked given the possibility of this being part of the parental experience. An important aspect of loss is what has been lost. Thus questions relating to parents' relationship with their child, their expectations and hopes prior to him becoming unwell may have given a more rounded picture of what they had lost. As a forensic social worker, one focus of my work is investigating the developmental history of newly admitted patients, including the impact of family dynamics. Perhaps it was a measure of how much I wished to avoid presupposing themes which may emerge from the study, that I avoided going down this path. However, as the interviews proceeded, participants did talk about what they felt they had lost in terms of the hopes and dreams they had held for their son as a child. Perhaps this reflected the strength of this aspect of their experience rather than because it was a focus highlighted in the interview schedule.

The questions that were included in the schedule perhaps reflect my own constructions of the various time frames being asked about. For example one question in the schedule related to dilemmas that they may face. The specific questions in the schedule were not invariably asked, as has already been noted the schedule acted as an aide de memoire, with the focus being on what participants themselves generated. Nevertheless, I had wondered whether there would be a dilemma for parents in telling the team that their son's mental state had deteriorated, when they knew that the outcome may be his recall to hospital. It is possible that another researcher may not have wondered about dilemmas that parents may face.

Further questions related to coping and support, perhaps reflecting my interest in what might help parents in this situation. My experience as a mental health professional in the forensic field led me to recognise that participants' experience may be life changing. A previous conversation with a father of a son now living in the community highlighted that his life had forever changed because of his son's offence and consequent status as a restricted patient, and that as a father he was now 'defined by the act'. This led me to include questions in the schedule as to possible changes in participants' thoughts and feelings over time. As a psychologist, I focused on questions that would illuminate psychological processes for parents. Perhaps someone with a medical background might have asked questions regarding the parents' construction of their son's mental 'illness'; while another researcher with less experience of forensic patients may have wondered more specifically about stigma.

6.3.3 Sample

In order to gain an in depth understanding of the studied phenomenon, IPA requires a homogenous sample. The parents in this study shared a common experience of a specific legal and service context. All three medium secure units were located in South East England, although from both rural and urban areas. Nevertheless there were no parents from inner city areas, who may have had a different experience. The study included both mothers and fathers, and came from a range of socio-economic backgrounds. IPA acknowledges that the findings relate to the specific individuals being studied, and the results from this particular study reflects the experience of these parents rather than necessarily applicable to all parents in

contact with conditionally discharged and recalled patients. Nevertheless, the interpretations that were produced for this group of participants may be helpful in terms of beginning to understand the experiences of other parents or close relatives of restricted patients who are conditionally discharged and then recalled to hospital. IPA is interested in meanings and processes rather than constructing a theory that applies to more general populations.

Approaching the participant was dependent on the consent of their son. There were similar numbers of patients who refused from both white and ethnic minority groups, but it was not clear whether black patients would have been more receptive to a non-white / minority ethnic researcher. It is possible that parents of sons who refused might have very different experiences from those whose sons consented. No parent refused to participate, and all were white British. One criterion for inclusion was that the patient was in contact with their parent throughout the conditional discharge and recall phases. Parents with less contact with their son may have had a very different experience than that expressed by participants in this study. It is also recognised that family units may experience the situation differently from individuals within the family. Nevertheless, the study aimed to explore the experience of individual parents from a phenomenological perspective. Although IPA does not seek to be generalisable, for the reasons outlined above, further research with different populations could suggest similarities and differences, for example parents from different ethnic and socio-cultural backgrounds; parents of daughters who are restricted patients, or parents of patients who have been again conditionally discharged and living in the community.

6.3.4 Interviews

Despite having general open ended questions prepared relating to the differing phases of the admission to hospital, conditional discharge and recall, the interviews proceeded along the lines of a conversation, with lines of enquiry being followed as they came up. Nevertheless, my own responses to participants' accounts may have encouraged them to speak more about some aspects of their experience than others. Additionally, the aspects of experience that I followed up would have involved a choice, even if I was not necessarily aware of this.

The study was introduced to parents as potentially producing results that might assist in helping other parents in a similar situation. It is possible that even this information may have led participants to predominantly reflect on their difficulties. However, they also spoke of positive aspects of their experience, such as the hope they held for their son, their mainly positive relationship with him, and of the support they received from others.

Parents gave retrospective accounts of their experience of the conditional discharge phase, although for some this was relatively recent. Hammersley (1994) suggests that retrospective recall bias can compromise accuracy. However retrospective accounts should not be assumed to be unstable or inaccurate and parents spoke of specific events which were associated with strong feelings, which may not have changed much over time. In encouraging parents to describe specific events I hoped that this would evoke the thoughts and feelings that reflected those they may have

had at the time. However their accounts describing their experience of their son's current recall was not retrospective, given that all the sons were still in hospital.

In the reflexive account below I have provided some thoughts regarding my own positioning during the interview process. My training as a counselling psychologist has enabled me to become more aware of my own processes while working with another. Specifically this helped me to remain fully involved during the interview in listening to the participant, while also being vigilant to my own responses to what they were saying.

6.3.5 Data analysis

IPA recognises that the data analysis will be largely dependent on the researcher's individual interpretations. The double hermeneutic process involves both the participant's voice and the researcher's focus of attention. The interpretative process necessarily prioritises which voice is attended to. A limitation of this is that there may be other aspects of experience that are not highlighted. What is important is that the analysis is transparent, so that the reader can see how the results have been achieved. I hoped that the interview schedule would not presuppose the themes and an examination of the schedule and the resulting themes from the data set suggests that participants were not directed towards particular ways of thinking. For example, themes relating to the system as impenetrable, 'expert', and difficulties with the team were not areas of specific enquiry. However participants were asked about their thoughts and feelings regarding their experience, reflected in the super-ordinate theme of emotional impact. For example, issues explored in the interviews included

any concerns, hopes and expectations they had; how they managed these, and what would have helped them. I entered the analysis stage with some excitement as to what might emerge, hoping that I would remain as open as possible to themes, including those which might prove to be unexpected. Reflecting on how this may differ for a researcher with limited experience of forensic services, I reflected that they may focus on specific issues which arose in the interviews such as the index offence; the criminal justice system, or what a forensic unit is like. Additionally because of my experience I was aware of the difficulties that parents face, particularly prior to initial admission, in obtaining the help of mental health services, and of impoverished community resources which limits the capacity of mental health professionals in working with families.

Although the analysis was my interpretation and another researcher may have noted other points, an independent researcher read through my analysis in order to see how the themes arose from the data, as a means of triangulation.

This study yielded a huge amount of rich data from the accounts given by parents in the interviews. There were many quotes which could have been used as examples to illustrate the themes and many were necessarily omitted which could have offered further illumination. The analysis was guided by a widely accepted procedure to identify themes from the data. The quotes were chosen to illustrate the themes that emerged from this analysis. Furthermore, participants gave rich accounts relating to their experience of both the pre-admission and admission phases. This could be used in future analyses, but for the purposes of answering the research question was necessarily set aside.

6.4 Validation

My analysis of the data in this study was necessarily a subjective process, whereby my interpretations unavoidably relied on my personal values and beliefs. IPA acknowledges the impact of the researcher and allows for the involvement of the researcher's values and beliefs in the analytic procedure (Smith, 2008). It is therefore possible that another person analysing the data would have generated a different interpretation because of their own unique values and beliefs. Despite the subjective nature of the analysis it is important to remain true to the data and I carried out validity procedures as outlined in 4.4.6.

6.5 Reflexive account

Reflexivity is regarded as a vitally important part of the collection and analysis of data (Nadin & Cassell, 2006). A variety of influences may impact on the interpretations generated, thus a reflexive stance is necessary in order to identify and understand what these influences are. An important component of IPA is bracketing which refers to the researcher acknowledging biases that they may bring to the research. By bracketing their biases, the researcher is better positioned to attend to the participants' account with an open mind (Smith & Osborn, 2008).

6.5.1 Researcher's position

6.5.1.1 Prior to the research

At the start of the research study I hoped that my findings might be instrumental in making a difference to parents in this situation, by illuminating their experience for other professionals. I hoped that my findings would influence the development of services which might alleviate the apparent stress and distress that such parents expressed. I was aware that participants may have different experiences to those which I was alert to, and wanted to learn from them. Despite my years of working in forensic services, I was not so arrogant as to believe that I already had a good grasp of what parents might experience, and particularly not in a situation where recall was involved. My reading of the forensic studies that had been published led me to expect that parents would experience relief when their son was admitted. More generally, I expected that the literature relating to families of the general psychiatric population in terms of loss, grief, and hope would also apply to this more specific forensic population, although I was not sure what else might emerge as significant.

On a personal level, as the mother of an adult son I had imagined the potential dilemma of wanting to help him if he were to be a deteriorating restricted patient in the community, while perhaps not wanting to inform professionals if this meant that he would perhaps be prematurely recalled to hospital. It was important that I be aware of and bracket my ideas in order to be open to possible disconfirming data.

6.5.1.2 Impact on the research process

A discussion of the researcher's impact on the development of the interview schedule has been included in paragraph 6.5.2. Prior to starting the study I had been working as a forensic social worker for ten years. This brought me into contact with parents of predominantly male patients admitted to a medium secure forensic unit, as well as those of conditionally discharged patients, and on one occasion I had been instrumental in recalling a patient to hospital. While working in the field I had listened to many accounts of parents who had struggled to get the help they knew their son needed from local mental health services before he committed the index offence, and their desperation that something had to happen before anyone would take notice. This experience may have impacted on the interview process in that I felt much sympathy towards them when listening to their struggles, and sensed their frustration with services. I also felt good to be part of the service that they perceived positively given that their son's admission signified the resolution of the battle they had engaged in to obtain help for him.

Although my prior experience may have helped me attune to the experience of the participants, I was aware that I was part of the very process that the participants were talking about. As a mental health professional in forensic services, I was thus part of the system that made decisions about their son. I had considered how this might impact on the research process wondering that they may moderate what they said. However the strength of their expressed feeling did not lead me to believe that they were inhibited by their knowledge of my professional association with forensic mental health services. It appeared that, on the contrary, they felt able to speak

about their experiences without the need to 'protect' me, or be concerned that I would be shocked by their accounts, or focus on any mention of their son's index offence. As one participant recounted, she was offered a parents support group at her local Community mental health centre. She found herself unable to speak about her experience of her son's index offence and admission to medium security when others in the group were concerned with what appeared to her to be their son's normal adolescent behaviour. Additionally, as a professional working within the forensic arena, the openness of their accounts may have been facilitated by an assumption that I would not stigmatise either them or their son because of his status as a mentally disordered offender.

In agreeing to take part in the research, a number of parents said that they hoped their participation would help others. This indicated that they saw me on some level as having power to highlight the issues that they raised. It is also possible that parents perceived me as a powerful instrument within the forensic system; able to achieve change; someone who could speak on their behalf and be a voice for them within a system which they so eloquently described as not giving them a voice. Yet the interview offered them an opportunity to recount their story and experience to a mental health professional within that same system. From a personal aspect, I brought certain qualities to the researcher-participant relationship which may have facilitated the parents' expression of their experience. Specifically, I am not usually confined by conventional thinking and am able to comprehend that the other has an equally valid viewpoint from their individual perspective. To some extent I was therefore able to listen to their accounts in a non-defensive manner, although there were exceptions which are discussed below.

As a forensic mental health professional, I am aware of the complex issues surrounding discharge, both in terms of assessment and management of risk; and acknowledging the apparent cautiousness of discharging bodies. I was aware that I responded to certain aspects of their articulated experience because of my experience as a professional working within the forensic field. For example, one participant described how she felt that professionals had written reports about her son, describing a specific incident. Whereas she normalised her son's behaviour in the incident, she complained that professionals had viewed it in terms of risk. I was aware that as she was giving me her account I felt some irritation and heard her description in terms of her minimising his behaviour. I was aware of my response as she spoke, and having duly noted it, reminded myself that it was important to understand her experience from her standpoint, not my own. I also wondered whether my response reflected that which parents perceived they received from mental health professionals when there is any disagreement between them. A number of participants had expressed that they felt they were regarded as a 'nuisance' to professionals. I was struck by how patronising my assumption was that I knew better, particularly in the light of the theme of 'the expert system', and by the understanding that however she or the professionals had interpreted this incident; this was her experience of how things were.

I was aware that parents often talked about their son and how they thought he would feel and think about a situation rather than of their own experience. I wondered whether this may reflect their close involvement with their son. However, Osborne and Coyle (2002) also noticed this when interviewing parents of sons diagnosed with

schizophrenia, and suggested that this may be a result of parents habitually speaking for their son and prioritising his needs over their own.

There were occasions when I wanted to help parents find the words they were looking for. My training as a counselling psychologist encourages me to try to enter the world of the other without imposing my worldview. Nevertheless it was hard at times to allow parents time and space to think about how to communicate their experience, perhaps as a result of my own experience as a professional within the forensic arena.

6.5.1.3 Impact on the analytic process

My analysis of the data in this study was necessarily a subjective process, whereby my interpretations unavoidably relied on my personal values and beliefs. IPA acknowledges the impact of the researcher and allows for the involvement of the researcher's values and beliefs in the analytic procedure (Smith, 2008). It is therefore possible that another person analysing the data would have generated a different interpretation because of their own unique values and beliefs. As I analysed the data, I was acutely aware of bracketing my thoughts and feelings so that I could adequately capture the participants' experience. Despite the subjective nature of the analysis it is important to remain true to the data and I carried out validity procedures as outlined in 4.4.6., including discussion of my analysis in supervision and maintaining a reflective diary.

I was mindful to how my personal experiences may have impacted on the analytic process. In particular, I may have been biased towards accounts which were consistent with the struggle that fitted with my own assumptions. My own personal experience of not being heard as a mother resonated with the accounts given by participants, and may have led me to attend to these aspects of their experience. My previous work with socially excluded people prior to becoming a social worker strengthened my belief that the marginalised should have a voice and be treated with dignity and respect, again themes that I noticed as prominent for the parents in this study. As an Approved mental health professional, I was especially aware of issues within accounts relating to assessments under the Mental Health Act. My clinical experience of working with parents within a forensic setting may, on the one hand, have enabled me to bring a greater sense of empathy to the analysis. On the other hand, I am aware of how my own experience as a forensic mental health professional may have left me feeling critical towards parents who did not appear to view situations from my professional standpoint, for example in terms of potential risk that patients may pose.

Throughout the analytic procedure, I remained cognisant of these possible biases and sought to keep them at the forefront of my mind in order to protect the analysis. This was achieved by the measures already mentioned (e.g. supervision and maintenance of a reflexive journal). I believe that these measures enabled me to monitor the possible impact of these biases; and in doing so ensure that the interpretations were anchored in the participants' accounts, rather than being my own established ideas.

6.5.1.4 Reflexions subsequent to the study

Based on previous research findings and my own professional experience, I had embarked on the study with a hypothesis as to what parents' experience might be. I had envisaged that if parents feel hope and relief when their son is admitted for treatment in a forensic unit (Nordström et al., 2006) then their reaction to his subsequent recall to hospital would be one of loss of hope. I had not taken account of the resilience of the human spirit, nor the constant hope that parents have for their children. Reflecting on my experience as a mother I realised that one never gives up hope, but that just as the parents in this study, the nature of that hope may change with circumstances.

Given the nature and purpose of conditional discharge, I was surprised to find that parents still found that their concerns about their son were not taken seriously by the supervising team. For patients who are so well known to the mental health services; with a well documented risk assessment and known history of a high level of risk associated with deterioration in mental state, I was shocked that parents in this study spoke of how difficult it was to get professionals to take notice of their concerns during their son's conditional discharge, and that professionals did not appear to respond quickly to these concerns. I was also surprised that there seemed to be such confusion as to where the boundaries of responsibility lay during conditional discharge.

I had also not previously been aware of the importance that parents attached to their son's "innocence" by virtue of his mental health. I had foreseen that parents would experience loss and grief when their son's mental health deteriorated, but their reappraisal of what they expected him to subsequently achieve demonstrated a resilience and positive attitude that was stronger than I had anticipated. I had wondered whether confidentiality would be an issue, but this was not directly raised by parents, possibly because of the purposive sampling; sons who agreed that their parent could be approached perhaps also agreeable to them being provided with information.

From my professional standpoint, I had thought that the service treated parents with respect, and that they were adequately prepared for their son's discharge. Hearing their accounts I was struck by the ways in which they feel excluded from the team. I noticed that they were not offered refreshments when they attended meetings, and treated as 'outsiders' rather than as part of a team working towards their son's progress.

The research process has changed me in that I am much more sensitive to the need to make parents aware that their knowledge of their son, their parental expertise, is invaluable. I am also more aware of how parents may perceive professionals and that this may be based on their historical experience. I am acutely aware of the status of parents when they are invited to contribute to discussions about their son, and when they are not so invited. On a personal level the study has re-humanised the experience of parents in this specific situation for me while also acknowledging the complexity of this phenomenon for the individual.

6.6 Implications for clinical practice and recommendations

Results from the present study suggest a direct role for counselling psychologists and other professionals working in forensic services with parents of restricted patients; and also indirectly through the ways that such services operate when dealing with parents. The recommendations made below must be viewed in the context of the following limitations:

1. The study explores the experience of individuals rather than whole families; it would be necessary for professionals working with family groups to be aware of the potential for different needs and experiences for families as a whole, and the individual members of the family.
2. Although recommendations have been made on the basis of themes that arose for parents within this very specific sample, the homogeneity of this group implies that the results cannot be generalised to other groups such as parents of daughters who are restricted patients; different cultural and ethnic groups; and parents in inner city areas. Nevertheless, inductive reasoning suggests that as the themes that arose from the study were widely held, these may well indicate transferability of the results to other parents.
3. In order to answer the research question, the sample was necessarily limited to those parents of sons who had been recalled. Thus the results do not necessarily reflect the experience of parents whose sons were successfully conditionally discharged in that they did not require recall to hospital. However, it could be hypothesised that the experience of the parents in this study was more difficult than that of parents whose son had a successful

return to the community. As with enquiry reports into homicides, 'worst case scenarios' can inform ways in which services can be improved; and in terms of how best parents can be prepared for their son's conditional discharge.

4. The sample did not include parents of sons who refused; or those parents who had no contact with their son. Conclusions cannot be drawn from their son's refusal, or whether parents had contact with him. Further research may illuminate these areas, and yield potential ways in which services could be improved. The recommendations made below are based on the themes that arose from the accounts of parents who were engaged with their son, and desirous of engagement with services.
5. One important theme that arose from the study was the loss and other emotional impact that parents experience when their son is conditionally discharged and then recalled to hospital. The study sought to provide a fuller understanding of the experience of parents regarding their son's conditional discharge and recall with the hope that this would help mental health professionals have a more empathic understanding and response to parents in this situation. Comment has been made that an even richer understanding of parents' experience could have been obtained if they had been asked about their relationship with their son as a child, and how this may impact on their current experience. Any recommendations regarding individual work with parents must take account of the fact that their experience will be unique, and that general assumptions cannot be made.

6.6.1. Implications for direct clinical practice with parents

For psychologists and other mental health professionals to work effectively with parents of patients within forensic services, it is necessary that they are aware of parents' experiences, which this study suggests may include fears, concerns, uncertainties, and feelings of grief, anger and powerlessness. Both the current study and others exploring parent's experience of forensic services (Canning et al., 2009) highlight that parents' trust in mental health systems can be damaged by their previous experience of an unresponsive service. Nevertheless parents experienced some optimism on their son's admission, and this may be the optimal time for mental health professionals within forensic services to work with them to develop a collaborative relationship that could then hopefully characterise the rest of the admission (see Beaupert & Vernon, 2011, within general psychiatry; and McCann et al., 1996, within forensic services).

Psychologists have appropriate skills and expertise to help parents acknowledge and understand their feelings and experiences, and how these may impact both on their own lives and on their relationships with their son and professionals. Direct work with parents may assist in identifying and working through any difficulties in the development of a collaborative relationship. Active outreach to parents would enable the provision of information, psycho-education, and a safe space where they could express their thoughts and feelings to professionals if they so choose and know that they will be heard and respected. Specifically for parents of sons within forensic services, part of that process may be helping parents to find meaning in their situation, explore the impact on their identity, and begin to find some resolution in

their son being treated within forensic services. It has been noted that given the extended admission, and the lack of relative autonomy for patients within forensic services, it may be particularly difficult for parents to view their son as independent; indeed, such a view may be unrealistic. However, acknowledging that parents may always feel some responsibility for their son, an optimistic but realistic approach may enable them to encourage an appropriate level of independence, and develop realistic expectations of him. In an attempt to tackle the confusion around responsibility when their son is conditionally discharged, parents should be given clear guidance by forensic mental health professionals as to what might signify deterioration in their son's mental state, and clear instructions for who to contact (and how) should signs of deterioration emerge (including out of hours contacts) prior to his conditional discharge. Psychologists within forensic services already work towards developing relapse prevention plans with patients prior to conditional discharge. Prior to their son's conditional discharge is perhaps an ideal time for parents to reflect on how they might deal with the dilemmas they may face should their son become unwell and these plans could form the basis of such discussions and guidance for parents, whichever member of the multidisciplinary team is involved. Acknowledging that parents have been doing what they can, they should be encouraged to identify and strengthen adaptive coping strategies and support networks, and given information regarding alternative sources of support. This work would acknowledge the stress that parents described, while enabling parents to value their strengths and identify alternative means of support.

A recommendation that psychologists provide an active outreach service to parents would have significant resource implications as this is not currently part of their role.

Nevertheless, research into the effectiveness of such work would usefully inform those who formulate policies and who influence the funding of service provision. Such research could assess whether psychologists should directly provide this work, or be available to supervise other disciplines such as nursing staff or social workers; or provide training for these disciplines.

6.6.2 Implications for clinical practice within the forensic mental health system

The message to forensic services from this study is that many parents feel poorly treated by professionals, and complain about the lack of collaborative working despite Governmental policy drive for mental health services to work in partnership with families and carers, including within forensic services (Department of Health, 2008a; Health Offender Partnership, 2007).

The responsibility to develop a collaborative relationship should not rest with parents, and partnership needs to be more than symbolic (Horrocks et al., 2010). Actively reaching out to families can reduce levels of distrust antagonistic to collaborative working (Eggenberger & Nelms, 2007). It is vital that medium secure services respect parents as expert care partners. (Department of Health, 2008a). It could be argued that because of the demands of public protection, within forensic services parents have even less influence over the treatment plan than within general psychiatric services. Nevertheless, their views, hopes and concerns about their son and his care and treatment should be sought, listened to, and treated respectfully. The Department of Health (2007) best practice guidance for adult medium-secure services states that ‘the views of patients, their carers and others should be sought

and taken into account in designing, planning, delivering and improving healthcare services' (standard E1, p.41), reiterated by the Royal College of Psychiatrists (2010) forensic quality network in their implementation criteria for adult medium secure units.

If parents feel that they are working as part of the team, this may reduce patterns of blaming. In particular psychologists are able to consider psychological patterns of functioning, both individually and in terms of group dynamics. Psychologists are often involved in supervising other disciplines, particularly nursing staff, who are often the first point of contact for parents. Negative attitudes towards parents could be regularly addressed within such a supervisory relationship. Professionals in general psychiatric services have highlighted that they do not always have skills in dealing with parents (Rose et al., 2004). Psychologists are able to provide training for all disciplines which could address skills deficits such as in conflict resolution, and encourage teams to reflect on the benefits of working with families, and ways in which they can actively collaborate. Forensic services should have a lead professional who will promote these issues for this marginalised group. The Princess Royal Trust for Carers and the Royal College of Psychiatrists (Partners in Care, 2010) developed a number of checklists for both psychiatrists and carers, including within forensic services, aimed at facilitating communication (Appendix 21). These could be routinely used by parents and professionals. Psychologists are involved in training of staff in forensic mental health units, and adding these aspects into the training menu may not be overly time or resource consuming, particularly if the advantages are perceived by staff.

It is important that professionals, who are used to working within the forensic mental health system, do not assume that their knowledge is shared by parents. Parents should be provided with information detailing how the forensic mental health system operates, as well as commonly used terminology. This should be followed up with regular opportunities for parents to ask questions of professionals outside of the meetings held regarding their son's progress. Wane et al. (2009) suggest that minimum standards should be established in general mental health services, specifying the level of contact or opportunities to meet the team and plan for the future. These standards could appropriately be applied to forensic services. Parents have identified feelings of isolation, and support groups within secure services may provide a system of reciprocal help (McCann, 1993). Given that this isolation may also be experienced by parents of conditionally discharged patients, support groups may wish to consider extending their invitation to such parents. Even if not providing such a support group directly, psychologists are able to offer their expertise regarding group dynamics and on psychological issues that may arise.

By the time their son has been conditionally discharged, parents are already aware that admission to forensic services can be lengthy. Professionals need to be aware that this prolonged admission may feel unacceptable to parents, particularly when he is already known to services when recalled. Where possible, parents should be given a plan of what the team expect to achieve before they will again support discharge. Despite Ministry of Justice guidance highlighting the importance of a seamless service when patients are conditionally discharged, the handover to local teams is not routinely accompanied by similar efforts regarding parents. Local teams may not prioritise working with parents because of demand for resources. Training for

medical and social supervisors should include emphasising the importance of such working, and a plan of contact between parents and professionals agreed prior to handover where parents desire this; bearing in mind the constraints of patient confidentiality. In particular, community services need to be both accessible and responsive and provide parents with a list of specific contact details of named professionals, including out of hours contacts. The Government (Department of Health 2008a) have already proposed that carers (parents for the purposes of this discussion) have a nominated keyworker with whom they could remain in contact. Parents are well placed to be an additional monitoring resource for the team as they may have more contact time with their son, following conditional discharge, than professionals. When so much is at stake; deterioration of mental health associated with heightened risk; it is vital that local teams develop a collaborative relationship with parents who remain in contact with their son. The Government may wish to consider the role of the Named Person as adopted by Scottish mental health services (Ridley et al., 2010). The Named Person has the right to receive documentation and attend Tribunals. Family members not nominated as the Named Person reported feeling undervalued by mental health professionals and constantly struggling to be recognised. In contrast, those nominated as the Named person felt that professionals listened to them and more willingly provided information (Ridley et al., 2010).

6.7 Implications for further research

Research is needed to investigate whether the experiences of parents in this study can be generalised to other groups, such as other family members, people in inner-cities rather than rural or suburban locations, and people with different cultural backgrounds and socio-economic status. Additionally how might the experiences of parents of daughters differ from those in this study? How might the family experience as a whole differ from that of individual parents? What are the different dilemmas that parents face and what influences their decision making processes? Remaining questions prompted by the findings of this study include: How do parents' identities change through the stages of their son's index offence, admission and discharge, and how might this impact on their relationships with their son, professionals, and others. How can professionals help parents manage the uncertainty associated with admission and conditional discharge? What are the barriers to collaboration both for parents and professionals both when restricted patients are detained in hospital, and when conditionally discharged, and how can these be addressed?

6.8. Conclusion

This study has explored the lived experience of parents of sons who have been conditionally discharged from a medium secure hospital into the community and who have been subsequently recalled to hospital. Using Interpretative Phenomenological Analysis a number of themes emerged from the experience of parents in the study. Themes related to the emotional impact on parents and to the responsibility they felt for their sons. The period of conditional discharge was characterised by uncertainty, together with feelings of frustration and anger when parents' concerns about their sons appeared not to be heeded by mental health professionals. A major theme for parents was their feeling of exclusion from the clinical team. The study offers in-depth and illuminating insight into the experience of parents in this situation. A number of recommendations have been suggested both in terms of direct work with parents, and also regarding how forensic services can collaborate with parents more empathetically and effectively.

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APPENDICES

Appendix 1: Letter to Responsible clinician

Dear Dr.....

Re: (Patient name)

As part of my professional doctorate in counselling psychology at the University of East London I am currently undertaking research into the experience of having a son conditionally discharged and subsequently recalled to hospital under section 37/41 Mental Health Act 1983.

You will see from the attached information sheet that I wish to ask patients for consent to approach their nominated parent(s) to participate in the study. Patients will be given information about the aims and nature of the research, and asked to sign a consent form (both attached), permitting me to approach their parent(s).

I would be grateful if you would confirm that (Name of patient) has capacity to consent to my approaching their parent(s) for the purposes of this research by signing and returning the form below.

If you wish to discuss this further, please contact me via email rosemary.steadman-allen@kent.gov.uk or rsa@kmpt.nhs.uk or by telephone either on 01622 723135 or mobile tel. xxxxxxx

Yours truly,

Rosemary Steadman-Allen
B.Sc (Hons); M.Phil (Cantab); M.Sc; Dip.SW.

Title of Project: The experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital. An interpretive phenomenological analysis.

Patient Name.....

I confirm / cannot confirm (please delete as applicable) that to the best of my knowledge, the patient named above is able to consent to Rosemary Steadman-Allen approaching their nominated parent(s) for the purposes of the above research project.

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

Name.....

Position.....

Appendix 2: Information sheet (Patients)

An investigation into the experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital.

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. Please ask 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. Thank you for reading this.

What is the purpose of the study?

Although we know that when someone is admitted to a medium secure forensic hospital, this can have an impact on their family, we don't know what it is like for families when the person has been conditionally discharged. And we know even less what it is like for families when patients have been recalled to hospital under S37/41. In order to prepare and support families even before the patient is conditionally discharged we need to have a good understanding of what families experience and how they cope in this situation.

Why have I been chosen?

As a patient recalled to hospital under Section 37/41 Mental Health Act 1983, your parent(s) may be able to help us understand what it is like to have a son conditionally discharged and then recalled to hospital. However I will need your permission to ask your parent(s) whether or not they would be prepared to talk to me about their experience.

Do I have to take part?

It is up to you to decide whether or not you are prepared for me to contact your parent(s) to ask if they would be willing to take part in the study. If you agree to me approaching your parent(s), you will be asked to sign a consent form. You can still withdraw your consent at any time without giving a reason. A decision not to take part, or to withdraw, will not affect the care and treatment that you receive.

What will happen next if I agree to take part in this study?

- I will ask you to tell me which parent you are agreeing for me to contact and how I can contact them to give them details of the study. If you are happy for me to see more than one parent, I would contact them both but they would be offered separate appointments. I will send the person you name some information about the research so that they can decide whether or not to take part.
- If your parent(s) agrees to take part, I will invite them to participate in an interview that would last about an hour.
- The questions they are asked will relate to their experience of having a son conditionally discharged and then recalled to hospital.
- The interview will be recorded on a mini voice-recorder and then transcribed, to make it easier to analyse.

- Your parent(s) will be given a thankyou payment of £15 for their time and as a contribution towards any travelling expenses.

Will the information from the study be kept confidential?

- If you agree that your parent(s) can be contacted, a copy of your signed consent form will be placed in your ward file and your Responsible Clinician (doctor) will be informed. No other information will be included.
- The interview with your parent(s) will be conducted confidentially, and their participation will not be shared with staff or patients. However if they were to provide information that you or anyone else is at risk of harm, then this would be shared with your Responsible Clinician (Psychiatrist) by talking to them and in writing. This is to make sure you and other people are safe. Your Responsible clinician would also be told (and in writing) if your parent(s) were to tell me anything which suggests that the (name of unit) security is at risk, or about intentions to abscond.
- All information provided during the semi-structured interview will be kept either in a locked filing cabinet or on a password-protected computer in line with the Data Protection Act. Only my supervisor and I will be able to see it. When the study has finished, this information will be securely destroyed.
- Once the study is completed, I will write a report on my findings, but you will never be identified as an individual – all people who take part in the study will be represented by an anonymous number. I will summarise the findings of the study in a general way so that you would not be able to be identified and to avoid any potential distress to anyone.
- The summary of findings may be used in a publication in a journal. All information will be anonymised.

Are there any risks involved in taking part?

It is not expected that there are any risks involved in taking part in this study, however, your parent may find that recalling and talking about their experience is difficult. They are free to refuse to answer any question at any time or stop the interview. However, it has been found that although people sometimes find talking about their experiences difficult, they often also find that it can be helpful as well.

Contact for further information:

Please contact me for more information, or if you have any concerns.

Rosemary Steadman-Allen
Trevor Gibbens Unit
Hermitage Lane,
Maidstone
Kent
ME16 9QQ
tel: 01622 723135

Thankyou for kindly taking part in this study.

(Please keep a copy of this information sheet and a copy of the signed Consent Form.)

Appendix 3: Information sheet (Participants)

An investigation into the experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital.

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 me 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. Thank you for reading this.

Why have I been chosen?

Your son is a patient who has been conditionally discharged and then recalled to hospital under S37/41 Mental Health Act 1983. He has suggested that you might be prepared to talk about your experience of this.

What is the purpose of the study?

I want to have a better understanding of what it is like to have a son conditionally discharged and then recalled to hospital. I hope that this understanding will help us prepare families more effectively for when their son is conditionally discharged, and also what support might be most useful for families at this time.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a Consent Form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you in any way. Your decision will have no impact on the care and treatment that your son receives in hospital. If you do agree to be interviewed but find any questions distressing, you do not have to answer them.

What will happen to me if I take part?

- I will telephone you to arrange a mutually convenient time and place for the interview.
- The questions you will be asked will relate to your experience of your son being conditionally discharged and then recalled to hospital.
- The interview will be recorded on a mini voice-recorder and will last approximately one hour.
- You will be paid £15 as a thankyou for your time and as a contribution towards any travel expenses. This research is not funded. However, it is not expected that you should have to cover any caring expenses incurred through taking part and these can be negotiated with the researcher in advance.

Will my taking part in this study be kept confidential?

- The interview will be conducted with you on an individual basis and in anything you say will be kept confidential. However if you were to provide information that your son is at risk of harm, then this would be shared with

your son's Responsible Clinician (Psychiatrist) by talking to them and in writing. The Responsible Clinician would also be told (and informed in writing) if you were to tell me anything which suggests that the (name of unit) security is at risk, or about any patient's intention to abscond. This is to ensure the safety of all concerned.

- All information provided during the interview will be kept either in a locked filing cabinet or on a password-protected computer in line with the Data Protection Act. Only my supervisors and I will be able to see it. When the study has finished, this information will be securely destroyed. All people who take part in the study will be represented by an anonymous number with any identifying information removed.
- Once the study is completed, I will write a report on my findings, but will summarise the findings of the study in a general way so that you would not be able to be identified and to avoid any potential distress to anyone.
- The summary of findings may be used in a publication in a journal. If so, all information will be anonymised.

Are there any risks involved in taking part?

It is not expected that there are any risks involved in taking part in this study, however, you may find that recalling and talking about your experience is distressing. If you do find any of the questions upsetting and would like to talk about this, please feel free to talk this through with me (contact details below). If you agree to be interviewed, I will also provide you with details of where you can obtain further support.

Contact for further information:

You are always welcome to contact me for more information, or if you have any concerns.

Rosemary Steadman-Allen
Trevor Gibbens Unit, Hermitage Lane,
Maidstone, Kent
ME16 9QQ
tel: 01622 723135

Thankyou for kindly taking part in this study.

(Please keep a copy of this information sheet and a copy of the signed Consent Form.)

Appendix 4: Consent form for patients

Title of project: The experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital. An interpretative phenomenological analysis.

Researcher- Rosemary Steadman-Allen

I have read the information sheet relating to the above study and have been offered the opportunity to ask any questions.

I understand that if my parent agrees to take part, this will be on a voluntary basis and that he/she is free to withdraw at any time without giving any reason. I understand that if they do not want to take part, this will not affect my care and treatment in any way.

I understand that my decision to consent or not will not affect my care and treatment in any way.

I understand that all interview data from the research will remain strictly confidential. Only the researcher and research supervisors will have access to the data. It has been explained to me what will happen to the data after the research study has ended.

I freely consent to Rosemary Steadman-Allen approaching the parent(s) I have nominated to ask them to participate in the study.

The parent(s) I consent to her approaching is

Name

Relationship to me.....

Name (if more than one parent nominated).....

Relationship to me.....

Name of patient.....

Signed.....

Date.....

Name of researcher: Rosemary Steadman-Allen

Signed.....

Date.....

Appendix 5: Consent form for Participants

Title of project: The experience of having a son conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital. An interpretative phenomenological analysis.

Researcher- Rosemary Steadman-Allen

I have read the information sheet relating to the above study and have been offered the opportunity to ask any questions.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I understand that I do not have to answer any questions during the interview that I would prefer not to.

I understand that if I refuse to take part, this will not have any impact on my son's care and treatment.

I agree to the interview being tape-recorded.

I understand that all data from the research will remain strictly confidential. Only the researcher and the research supervisor will have access to the data. It has been explained to me what will happen to the data after the research study has ended.

Name of participant.....

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

Name of researcher: Rosemary Steadman-Allen

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

Appendix 6: Interview Schedule

Introduction

I am not looking for 'right' or 'wrong' answers', I am interested in your experience.

Review information sheet and consent form

Time frames:

1. Admission/ before conditional discharge
2. Conditional discharge
3. Recall

When (name of son) was admitted / conditionally discharged / recalled what was your perception of his mental state? (What did you notice?)

How did you feel when he was admitted / conditionally discharged / recalled?

Concerns / worries / fears

Expectations

What did you think it would be like?

How did you manage (emotions mentioned above)?

Anyone spoken to about concerns?

Feelings about speaking to someone

Any dilemmas?

What help / support did you get to manage (emotions mentioned above)?

What would have helped to manage (emotions mentioned above)?

What was the effect of the admission / conditional discharge / recall on your relationship with (name of son)?

What was the effect of the admission / conditional discharge / recall on your own life?

Relationships with others

Work, finance, social life

Looking back on this time from the present, how do you feel now?

Looking back on this time from the present, how do your thoughts compare?

Additional questions re Conditional discharge

What were your feelings about (name of son) being supervised?

Understanding of conditions of discharge

Reactions from others?

Additional questions re Recall

Can you tell me about the events surrounding the recall of (name of son) to hospital?

Appendix 7: Directory of support

Directory of support for carers/relatives of patients at Medium Secure Units

Thankyou for agreeing to be interviewed about your experience of your son being conditionally discharged and then recalled to hospital. The interview may have raised issues for you regarding which you would like further support. The following are possible resources that you might find useful listed in alphabetical order.

Benefit enquiry line for information and claim forms

Tel 0800 882200

Textphone: 0800 24 33 55 <http://www.dwp.gov.uk>

Black & Minority Ethnic Carers' Support Service (BMECSS)

Selby Centre Selby Road, London N17 8JL; Tel: 0208 808 5510

or 0208 801 5530 Website: www.bmecarers.org.uk

Carers Christian Fellowship regular newsletters and links with other carers, occasional fellowship days arranged Tel: 01793 887068

Carers First provides support for carers in West Kent

192 High Street, Tonbridge, Kent, TN9 1BE; Tel: 01732 357555

Website: www.carersfirst.org.uk

Care for the carers provides support for carers in East Sussex

1st Floor, Greencoat House 32 St Leonards Road, Eastbourne, East Sussex BN21 3UT; Tel: 01323 738 390

Website: www.cftc.org.uk

Carers in Oxleas A charter of what support you can expect to receive and how to access such support has been produced by Oxleas Trust. It can be found on the internet from the following link:

<http://www.developbromley.com/public/FinanceandAdvice/Tools/Information.Handbook.For.Carers.pdf>

Carers UK Offers a telephone support carers line: Freephone 0808 808 7777 - 10am-noon, 2-4pm (Wed/Thur) www.ukcarers.org.uk

Cruse Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support, information, advice, and education.

Helpline Tel: 0870 167 1677

Email: helpline@crusebereavementcare.org.uk

Website: <http://www.crusebereavementcare.org.uk>

Depression alliance information and support for people who suffer from depression and their carers Tel: 0845 1232 320 Website: www.depressionalliance.org

First steps to freedom support for people with stress and anxiety related disorders. Also help for people with borderline personality disorders and their carers. Includes helpline, telephone counselling. Tel: 01926 864473

Hearing voices network helpline and support service for people who hear voices, their families and carers Tel: 0161 834 5768

Manic depression fellowship advice, information and publications for people with manic depression and those concerned about them Tel: 0207 793 2600
Or 08456 340 540 Website: www.mdf.org.uk

Mental Health Carers Support Association Tel: 0208 885 2006

Mental Health Foundation Tel: 0207 802 0300
Website: www.mentalhealth.org.uk

MIND

Information service Tel: 08457 660163 Mon-Fri 9.15am-5.15pm
Website: www.mind.org.uk

National Drugs helpline (24 hour) confidential advice, information and support for anyone concerned about drug use whether their own or someone else's.
Tel: 0800 776600

No Panic information, helpline, telephone counselling etc re panic attacks, phobias, obsessive compulsive disorders or other anxiety disorders
Tel: 0808 808 0545

Rethink Website: www.rethink.org

Rethink National Advice Line: 0207 840 3188 or 0300 5000 927 (open 10am – 1pm Monday – Friday) or email: advice@rethink.org

Rethink BME Carers support service in Kent Tel: 01474 364498

Samaritans Helpline (24 hrs): 08457 909090 Website: www.samaritans.org

Saneline helpline for people with depression and other mental health difficulties and their carers Tel: 08457 678000, 6pm-11pm every day of the year.
Website: www.sane.org.uk

Appendix 8: University of East London Research Ethics Committee Approval letter



Amanda Roberts

Psychology School, Stratford

ETH/12/58

Dear Amanda,

Application to the Research Ethics Committee: The experience of having a close relative conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital. An interpretive phenomenological analysis. (R Steadman-Allen).

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you. The Research Ethics Committee should be informed of any significant changes that take place after approval has been given. Examples of such changes include any change to the scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

A handwritten signature in black ink, appearing to read 'J. Steadman-Allen', is located at the bottom left of the page. The signature is written in a cursive style with a long horizontal line extending to the left.

Simiso Jubane

Admission and Ethics Officer

s.jubane@uel.ac.uk

02082232976

Research Ethics Committee: ETH/12/58

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:.....Date:

Please Print Name:

Appendix 9:

National Committee of Research Ethics Approval letter



National Research Ethics Service

South East Research Ethics Committee

South East Coast Strategic Health Authority
Preston Hall
Aylesford
Kent
ME20 7NJ

Telephone: 01622 713048
Facsimile: 01622 885966

28 October 2010

Ms Rosemary Steadman-Allen
Trainee Counselling psychologist
Kent County Council
Trevor Gibbens Unit, Hermitage Lane
Maidstone
Kent
ME16 9QQ

Dear Ms Steadman-Allen

Study Title: The experience of having an adult child conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital. An interpretive phenomenological analysis.

REC reference number: 10/H1102/49

Protocol number: RETH/12/58 (UJEL ethics)

Thank you for your letter of 22 September 2010, responding to the Committee's request for further information on the above research (and submitting revised documentation).

The further information has been considered on behalf of the Committee by the Chair's Panel.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation (as revised), subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		
Protocol	V1	14 July 2010
Academic Supervisor CV		
Letter to Patients (Appendix 2)	2	06 September 2010
REC application		30 June 2010
Covering Letter		14 July 2010
Letter from Sponsor	Letter UEL 2	14 July 2010
Interview Schedules/Topic Guides	1	14 July 2010
Letter of invitation to participant	2 (appendix 5)	06 September 2010
GP/Consultant Information Sheets	2 (Appendix 1)	06 September 2010
Participant Information Sheet: Appendix 3 (Participants)	2	06 September 2010
Response to Request for Further Information		22 September 2010
Participant Consent Form: Appendix 4 (Patients)	2	06 September 2010
Participant Consent Form: Appendix 6 (Participants)	2	06 September 2010
Letter from UEL - Amanda Roberts		30 June 2010
Evidence of insurance or indemnity	Letter UEL 2	14 July 2010
Referees or other scientific critique report	UEL Ethics Approval	14 July 2010
Participant Information Sheet: Appendix 3a (Patients)	1	06 September 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1102/49

Please quote this number on all correspondence

Yours sincerely



AP

**Dr L. Alan Ruben
Chair**

Email: dean.beattie@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Professor Rachel Tribe*

Appendix 10: Kent NHS Research Ethics Committee Approval letter



Comprehensive Local Research Network for Kent and Medway
Preston Hall
Aylesford
Kent, ME20 7NJ
Tel: 01622 227369
Fax: 01622 711295
Email: pdodds2@nhs.net

Reference: Proposal 888/Approval Letter/Version 1.0 (14/07/2010)

Ms Rosemary Steadman-Allen
Kent County Council
Trevor Gibbens Unit, Hermitage Lane
Maidstone
Kent
ME16 9QQ

Thursday 11th November 2010

Dear Ms Steadman-Allen,

Re: (Proposal 888) An investigation into the experience of having a son/daughter conditionally discharged under Section 37/41 Mental Health Act 1983 and then recalled to hospital.

I am writing to inform you that the above-named project has been approved by Kent and Medway NHS & SC Partnership Trust (KMPT) for work involving assessment of patients recalled to hospital under sections 37/41 of the Mental Health Act of 1983 and gaining consent to interview their parents and carers.

This approval requires that the work is carried out in accordance with the principles set out in the Research Governance Framework for Health and Social Care (Second Edition, DH 2005) and the Data Protection Act (1998). The current version of the Protocol is Version 1.0 (14.7.10). The CLRN (see contact details in the header of this letter) should be informed immediately if any of these criteria are to be changed.

Conditions of Approval

- 1. Sponsorship of study** The University of East London will act as research sponsor; KMPT is not responsible for the design and conduct of the study.
- 2. Confidentiality** You are required to ensure that all information regarding participants remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of



Directors: Dr David Smithard, Dr Chris Fox
Hosted by: Maidstone and Tunbridge Wells NHS Trust

The Kent and Medway Comprehensive Local Research Network operates as part of the NIHR Comprehensive Clinical Research Network in England. It is part of the National Institute for Health Research and forms part of the UK Clinical Research Network. The Networks support and deliver high quality clinical research studies.

information is an offence and such disclosures may lead to prosecution.

3. Study progression

You will inform me of any significant developments that occur as the study progresses, including notifying me when the study has been completed and sending me the final report and details of any publications, dissertations, abstracts etc., which may result from the study, so that our records can be kept up to date.

Finally, I wish you every success with the study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Peter F. Dodds', with a stylized flourish at the end.

Dr. Peter F. Dodds

Research Management and Governance Coordinator, Kent and Medway CLRN

copy to: Rachel Tribe (Academic Supervisor and Sponsor's Representative)

Appendix 11: Oxleas NHS Research Ethics Committee Approval letter



Research Study Approval Notification

This notification confirms that the research study named below has been approved by the Research and Development Office of Oxleas NHS Foundation Trust:

Title:	<i>The experience of having a relative recalled under S37/41 MHA v1</i>
Chief Investigator:	<i>Rosemary Steadman-Allen</i>
Local Investigator:	<i>Susan Sturdy</i>
Date:	<i>13/12/2010</i>
Approved by:	<i>Anthony Davis, Research and knowledge manager</i>

This research study may therefore be undertaken. Please note that approval is **contingent upon the following:**

- The Chief Investigator or Principal Investigator will **immediately notify** the Research and Development Office of the Trust should any changes be made to the original IRAS application as any deviations will render this approval notification void.
- The Chief Investigator or Principal Investigator will send an **executive summary** of the findings of this research study to the Trust's R&D Office for uploading to the Trust's intranet, and also provide the **total number of people recruited** to it.
- For **clinical psychology trainees only**, the Chief Investigator will provide **feedback** (written and/or a presentation) to the **service/team hosting this study**.

For further information please contact:

Anthony Davis, Research and knowledge manager

Oxleas NHS Foundation Trust, Pinewood House, Pinewood Place, Dartford, Kent DA2 7WG

Tel 01322 625700 x5032

Fax 01322 557664

Email anthony.davis@oxleas.nhs.uk

Appendix 12: Example of first coding of interview (Clare)

Initial analysis	Transcript P1 (Clare; lines 184 - 254)	Emerging themes
<p>Pleased at discharge because of close monitoring. Fear re non compliance with medication; she knows son, his disorganisation (can't contain self); Slip- slippery slope, progress reversed. son dismisses diagnosis</p> <p>'Whole thing' backsliding extensive impact. Worry materialised so she did know better than the 'experts'</p> <p>Voicing frequently but fears dismissed; 'can't happen'. 'We know', they and not she are the experts</p>	<p>C I was really very, very, very pleased about that because he was still being very well watched over at that point. My fear all the way through when discharge started to be talked about was that he wouldn't keep his medication up. Now this was partly because Michael is so disorganised, even now. He is so disorganised and once it starts to slip then he stops seeing the purpose of it, and he has never, at that point he didn't really accept he had schizophrenia. He said, 'well they say I have, they say I need it'. So, so that was my worry, that he would not take his medication. And that the whole thing would backslide, which is what ultimately happened.</p> <p>R mm</p> <p>C And I voiced that frequently. And I was told absolutely, categorically, this could not happen. He was going to be supervised. 'We will know if he</p>	<p>Containment by others / system, responsibility handed to professionals. Fears for son Mother's knowledge of son Personal containment lost when ill / no support.</p> <p>Uncertainty of mental state Fears for son realised</p> <p>Having no voice; professionals dismiss concerns. Professionals assume their knowledge is superior than mother's</p>

<p>Relating to her comment that he did backslide</p> <p>She continues to speak despite being dismissed Supposed to be supervising- but apparently not Powerful system apparently powerless Evidence showed that she does know son better than the 'experts'. Frustration at not being heard</p> <p>Return to feeling scared – refers back to the 'madness in his face', son 'contains' madness. Huge relief at recall associated with relief from fear, mirroring what she felt on his admission.</p>	<p>doesn't take his medication', but...</p> <p>R It didn't work out</p> <p>C It didn't work out. I spent six months at least from Christmas until the time he was recalled in the middle of July I spent telling the people who were supposed to be supervising him that he wasn't- that 'he's not taking his medication, I know he's not, I just know it'. And they 'well, we can't do anything, you know, until we have the proof'. I said 'but, you know, I know he's not taking it, I know he's not well'</p> <p>R mm</p> <p>C And before, just before he was recalled, if this isn't, sort of jumping ahead too much, I saw again, that same awful look in his face that I saw when he was seventeen, and I was really scared again at that point, and I was hugely relieved when he was recalled.</p> <p>R Yeah</p>	<p>Promised containment ineffective</p> <p>Professionals assume their knowledge is superior than mother's Mother knows son Not heard by professionals/ having no 'voice'</p> <p>Fear of violence / madness in son Containment by forensic system of son and what is in him.</p>
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<p>Relief at recall associated with mother's loss and grief- broken heart. She had done what she could to help (sending him out into independence?)</p> <p>Loss of what son had gained 'All' was going to be thrown away- materially and son's progress? Felt unnecessary then but meaning found in retrospect. Seeing the positives; he has learned a lot, accepts diagnosis (medical model?). Leap forward as opposed to backsliding.</p> <p>Process of her dealing with his 'backsliding': notices danger signs; rationalises: it's her imagination; tells herself he's all right; notices signs he's OK; talks to him about it (she still has a voice with him); reassurance- she believes him; he puts her mind at rest. Drinking seen as bad for him. He reassures her, accepts her premise about drinking too much</p>	<p>C Although it broke my heart, because he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful. And I, just the thought that he was losing that and it was all going to be thrown away, that (...) and it was all so unnecessary, or it seemed it to me, although now, at this point I think there was a purpose in it, in that he has learned a lot from it, and he, he does now actually accept that he is schizophrenic, which is a tremendous leap forward I think.</p> <p>R Yeah. So when, when was the first time that you thought that there was a bit of a slip, what did that make you feel?</p> <p>C Well, I suppose, I suppose the first few danger signs I tried to rationalise, you know, and think perhaps I'm imagining it and I'm sure he's all right, and he'd come back and he'd seem to be OK. I used to talk to him about it, because he was drinking you see which was bad news, and I'd talk to him about it and he'd say, you know when he was first beginning to backslide, he would reassure me and say, 'No, no, it's all right Mum, I know, OK, yes I've been drinking a bit much and I'm not</p>	<p>Loss of progress / hopes for son</p> <p>Loss of hope - futility</p> <p>Seeing the positives; optimism, and hope (process)</p> <p>Uncertainty: ambiguity of mental state</p>
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<p>He withdrew into himself, didn't bother to try- she feels he still has a measure of potential control; too far gone, loss of control now.</p> <p>Son physically present but not emotionally. Loss of communication channel (mirroring the lack of communication with the team, who were physically there but not listening to her)</p> <p>Referring to comment she had made</p>	<p>going to', and, and put my mind at rest. But then later on, he, you know he just went completely, withdrew into himself, didn't even bother trying to (...) but he was gone too far then</p> <p>R Did he withdraw from you and from family?</p> <p>C Um, not physically, he still kept coming round, but within himself he was, you know you could see he had gone back into his own world. We were irrelevant and when I drove him back to (<i>discharge placement</i>) he barely spoke to me; he was just there in the car. And if I spoke to him, he didn't, he couldn't seem to take in what I was saying, however mundane it was. I mean he was really, really ill again, really bad.</p> <p>R So you were scared</p> <p>C Yeah</p> <p>R About what, about what....</p> <p>C I didn't personally feel physically intimidated by him, I mean he</p>	<p>Not 'heard' as a mother, no communication / voice with son Containment ineffective</p> <p>Loss of relationship / communication with son Uncertainty of relationship</p>
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<p>Not intimidated by son despite him being full of anger and 'big' He didn't 'turn' on her Scared for him, for others. He is uncontained again</p> <p>Not just scared because he is getting into fights but what he might do; what he is potentially capable of</p> <p>Scared of what those he mixes with might do to him Dangerous environment, including 'nasty things' unspecified</p>	<p>didn't turn on me, but I was very scared because he had that, he said he was full of anger, and he was getting into fights so I was scared for him but I was also scared because he's a big strong boy and I was very scared</p> <p>R About what he might do?</p> <p>C Of what might, yeah, what he might do to other people</p> <p>R Yeah</p> <p>C And you know, what might happen to him, because the people he was mixing with, you know there were knives, and all sorts of nasty things</p> <p>R So you'd drop him off [<i>to discharge placement</i>] and not know</p> <p>C Yeah</p>	<p>Fear for son Fear of actual violence Loss of personal containment when ill</p> <p>Fear of potential violence? / actions towards others Uncertainty of son's actions</p> <p>Fear for son's safety</p>
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<p>Attention to normal sounds potential heightened and appraised as possible danger signals connected with son. Links to prior comment about attention being diverted away from her other children</p> <p>Gradual deterioration Feeling scared for nearly a year? 'Inklings' of things not being 'right'.</p> <p>Relating back to her previous comment</p> <p>She stays involved even though she has not been taken seriously by professionals, again mirroring her experience pre admission Effectively denied a voice even though she has been ostensibly given one; 'lip service'? 'I don't know' a sarcastic comment as to how she feels he is perceived.</p>	<p>R what was going to happen? Did you ever sort of picture in your head what might; how far it might go?</p> <p>C Not so much that, but I, if the phone ever rang late at night, or whenever I heard a police siren, at the back of mind it was always, you know, is that something to do with Michael?</p> <p>R Yeah, was that, how long did that go on for?</p> <p>C Well certainly, probably the best part of a year actually, from the first inklings that things were, were not right.</p> <p>R And you tried to talk to him about it</p> <p>C Yeah, initially. And I've always gone to his review meetings and been involved because he's always been willing for me to be, and um, but they would never, never, you know, just like when he was a teenager, I'm not the professional, so I don't know</p>	<p>Fear for son Uncertainty Hypervigilance to threat</p> <p>Uncertainty; ambiguity of mental state</p> <p>Responsibility assumed by mother Responsibility shared with professionals Feels that professionals assume their expertise is superior Having no voice? Professionals not listening?</p>
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Appendix 13: List of emergent themes from 1st coding (Clare)

Containment

Searching for containment (Different diagnoses when growing up)
Trying to get help for son
Inability of agencies to contain son
No end to her search for containment
Unheard- no one taking it seriously until he got into trouble
Son can't contain his madness anymore
Son contained on admission so safe
Relief when son contained (admission)
Diagnosis seen as containing
Containment of high security seen as 'a turning point'
Ineffectiveness of medium security to contain son
Containment by team seen positively
Reassurance from professionals able to monitor son
Grateful for supervision of son
Son contained by monitoring
Containment of son seen positively; can't do his own thing
Containment seen as positive to prevent son backsliding
Containment of restriction order seen positively.
Mother tries to contain son when he deteriorates
Containment hindered and so ineffective because of patient's rights
Inability of professionals to contain son
Disappointed with the supervision by professionals (ineffective containment)
Ineffective containment of son seen as letting him down
Containment only temporary/ineffective
Son can't contain himself when unsupported / not monitored
Mother tried to contain son when she saw him deteriorating
Inability to contain son when he had become so unwell
Parallel to pre admission, things have to get 'so bad' before anyone will do anything;
Professionals leaving things as long as possible before containing son
Professionals unwilling to contain son based on mother's perceptions
Son can't contain himself because of disorganisation
Son can't contain himself because unwell
Son uncontained- full of anger, getting into fights. Scares mother
Mother being cruel to be kind in seeking recall to contain son again
Mother would say she thinks he should have a condition of no alcohol, thinks that is what son needs
Containment seen as promoting son's welfare, so prioritised by mother over relationship
Would ask for no alcohol condition even if it affected her relationship with son
Wants son to be contained for his welfare
Wants son not to be allowed alcohol or stop medication despite knowing he wants freedom
Containment seen as protection

Worry and Fear

Of son seriously harming others or self
Fear because son holding it together and able to deceive professionals
Fear dismissed by professionals
Constant worry about son
Worry about influences on son
Worry about his financial coping
Fear for son: what might happen to him
Fear for son, not taking meds
Heightened attention to possible danger and this associated to fear for son
Fear of son because he was full of anger, what he might do to other people
Fear of madness in son (in his face) parallel to when he was 17
Fear of son (facial expression in son)
Scared similar to pre admission
Fears realised associated with dashed hopes
Fears realised when son not supervised adequately
Fears realised, discovering mess when she cleared out son's flat
Fears that son would deteriorate after his non-compliance with meds
Fears realised when she saw him deteriorating
Fears realised when son was in a 'terrible mess'
Fear realised that son would fight
Fears of his self-neglect realised
Fear associated with her imagining her son would get into a fight
Fear prior to discharge that he would stop taking medication
Worry that son would go out drinking

Having no voice

Not taken seriously
Dismissed by husband
Concerns ignored by husband
No help until son broke law, police involved
Considered fussy and neurotic by team
Just a mother
Need to keep asking for assessment
Daughter has no voice – didn't tell mother her own fears
Has no voice at son's review meetings
Professionals echo husband in minimising her fears
Team not listening parallel to pre admission
Professionals not listening to her request for recall
Frustrated by token involvement
Fears dismissed by professionals
Trying to tell people about son's deterioration
Not taken seriously by professionals
Telling professionals son taking drugs but them not acting
Professionals not interested
Professionals not taking her concerns seriously because they don't have proof
Told to go away
Nobody listening

Ignored by professionals
Sidelined
Tolerated but seen as a nuisance
Professionals not taking any notice
Son not taking any notice of her
Concerns dismissed by son
Worry dismissed by professionals
The unspeakable, unable to name the high secure hospital or tell anyone

Having a voice?

Asked if she would tell professionals if son non-compliant with medication
Tries to tell professionals; constantly phoning despite being ignored
Professionals only listening superficially, but really not interested
Asked if she had any concerns
Honest with son
Tried to talk to son to get him to change behaviour
Son agrees she has her own opinion
Listened to by professionals when son finally recalled

Loss

Of normality, 'normal family life'
Of perspective, questioning normality once son gone
Of family time because trying to deal with son's problems
Loss of hoped for progress, heartbroken
Gradual realisation of loss of hopes seen as death of all the hopes and expectations
Loss of hopes for child a time of grieving
Deterioration of son involved process of 'coming to terms with it', acceptance
Loss of hopes painful, sudden, repeated
Loss of hopes for son an 'immense, huge sadness' related to potential as baby
Loss of progress, all thrown away
Gradual loss of illusion of control
Can see what son has to lose if recalled; doesn't want to precipitate
Psychological loss of son
Feels son saw her and family as irrelevant
Loss of progress seen as unnecessary
Loss of time with extended admission and recall
Heartbroken that he was losing everything he had gained.

Optimism and hope

Optimistic once son diagnosed
Illusion of control, ability to get son's life in order
Finding the positives; high security difficult but also a 'turning point'
Optimism associated with diagnosis / label as something now in control
Optimism associated with gradual improvement
Hope that son would have a productive, normal, stable future
Optimism once diagnosed, as treatment will follow and then cure
Optimism that son would be cured 'put right'
Restriction seen as a good thing
Seeing the positives, son has learned from recall

Seeing the positives, sorted out son's financial difficulties
Seeing purpose in recall
Seeing the positives, since recall son has progressed
Realistic hopes, accepting son's disorganisation
Complex feelings at recall; heartbroken, but really pleased

Powerlessness

Can't get professionals to take notice until law has been broken
Powerless because she was perceived as the one with the problems
With team who are the 'experts'
Family walking away because powerless to do anything
Nothing friends could do
Help ineffectual, doesn't last long
Gives up because can't 'make things right'
I can't do anything else; I'm doing what I can
Powerless because not part of care team
Powerlessness because patronised by team
Powerless because sidelined by team
Mother's powerlessness; 'nothing I could do' (to get team to listen)
Team feel her son is not her business
Powerlessness engendered by team who she feels want her to go away
Powerlessness almost fatalistic when she recognises nothing she can do
Powerlessness in getting son to take notice of her and change behaviour
Powerlessness associated with team's refusal to recall, associated with frustration and worry
No control over son or situation
Powerlessness parallel to pre admission, when doctors don't act
Powerlessness parallel to pre admission when people who have power don't act until something happens.

Responsibility

No support from husband
Taking responsibility to get son diagnosed when growing up
Felt blamed for having problems
Other agencies saying it is not their problem
Family are left responsible, have to manage
Mother takes responsibility to get son's life in order but it is illusory
Trying to get help for son, asking for assessment
Team say they are the experts; assume responsibility?
Team's responsibility for son, who can't do what he likes
Team's responsibility for son, keeping an eye on him
Team's responsibility for son, recall if he 'steps out of line'
Responsibility given to mental health professionals; diagnose, treat, 'put it right'
Responsibility for situation attributed to mother by critical family
Team's responsibility for son to monitor him
Responsibility shared seen positively
Professionals excused when not sharing responsibility because of lack of resources
Family absolve themselves of responsibility, when there was nothing they could do
Avoidance of responsibility by placement manager

Avoidance by mother; not wanting to precipitate recall
Responsibility avoided by professionals through not taking problems seriously
Professionals assume responsibility for recall
Trying to share responsibility with professionals
Responsibility not shared with professionals because excluded from team
Responsibility shared with professionals; grateful son being supervised
Responsibility shared with professionals; mother reassured they will monitor son
Avoidance of responsibility by professionals until something bad happens
Son not taking responsibility for himself
Unable to take responsibility because nothing she can do
Can't share responsibility because professionals don't see it as her business
Family assume lifelong responsibility
Takes responsibility for telling team even though she knows consequences for son
Mother assumes responsibility when son deteriorating
Mother recognises lifelong responsibility
Older son's attitude that patient should assume responsibility
Faithful responsibility, always been involved
Mother's responsibility; doing the best for your child
Practical doing what she can
Responsibility given to professionals as mother recognises their expertise
Mother resumed responsibility on recall

Uncertainty

Uncertainty of feeling, confusion
Uncertainty as to whether son will harm others or self
Uncertainty as to son's potential violence
Uncertainty of how long the situation will last
Professional uncertainty regarding son's diagnosis prior to admission
Uncertainty of diagnosis / behaviour
Uncertainty of length of admission
Uncertainty of treatment, longer and more complicated
Uncertainty that son might be deteriorating
Inability to communicate with son
Uncertainty of progress
Uncertainty of progress when admitted to high security
Uncertainty of hoped for progress then seeing son's deterioration
Uncertainty of son's deterioration, 'slipping back / sliding'
Uncertainty of son's insight when he starts to slip
Uncertainty of relationship with son 'gradual shutting off '
Uncertainty of son's deterioration and whether she can do anything to stop it
Uncertainty of how long it will take for son to get well again
Suspecting deterioration
Process of uncertainty regarding deterioration: rationalising signs in terms of
imagining, talk to son seeking reassurance, mind put at rest
Uncertainty as to son's ability to manage financially in community
Uncertainty when hearing noises (phone ring, siren); whether they relate to son
Uncertainty as to how son would act in community (drink, not take medication)
Uncertainty of what son might do to others or what might happen to him associated
with fear.

Ambivalence of feeling on recall, heartbroken and pleased
Uncertainty as to how long it will take for son to be discharged again

Coping

Through being honest with others, she gets more support
Support from sympathetic friends
Coping attitude, facing the worst that can happen
Coping through humour
What would have helped; being taken seriously
What would have helped; team retaining their autonomy but listening to her
What would have helped; team monitoring son more closely
Reassured that son could cope now

Impact on relationships

On family who see son as their lifelong responsibility
Mother felt excluded by professionals
Mother felt tolerated by professionals and a 'bit of a nuisance'
Mother felt dismissed by professionals
On oldest son who'd 'had enough'
On oldest son, who was angry with patient
On relationship with son, gradual shutting off from his family
On family who were walking away from the situation
On family, all very worried
On daughter who cut herself off from him
On daughter who couldn't cope with it
On daughter who was knocked sideways
On daughter who had worked hard to rebuild a relationship with him, now cut off
On potential relationship with son if she told professionals he was deteriorating
On relationship with son, thinking that she is stupid and taken in by professionals
On relationship with son, who has perceived her as being on the 'wrong side'
On relationship with son, his welfare is paramount over her relationship with him
On relationship with son, No relationship if not well
Risks relationship with son for his welfare
On relationship with son, thinks he would be angry if she wanted control imposed
On relationship with son, would ask for no alcohol condition in front of him despite incurring his anger because she thinks it would help him

Knowledge of son

Mother sees son's deterioration when he can't
Mother telling professionals son is deteriorated
Recognition prior to discharge that mother might know if son non-compliant
Mother's knowledge of son marginalised by team
Mother recognised son taking drugs
Mother knows son's history suggests non-compliance and rapid loss of insight
Mother knows son not taking medication and unwell
Mother recognises lack of medical expertise but still knows son unwell
Mother's knowledge of son marginalised by team because she's not qualified
Mother recognises son's mental state similar to pre admission
Mother's knowledge of son and consequent concerns dismissed

Professionals dispute mother's knowledge of son
Grateful that professionals will know if he is taking drugs
Reassured that professionals will know if he is non-compliant
Professionals blamed for not noticing what she had known
Professionals assume their expertise is superior
Professionals assume that they will know if he is non-compliant
Mother acknowledged medical expertise superior regarding medical issues

Appendix 14: Table of themes from 1st coding (Clare)

Super-ordinate theme	Theme	Quotes
Having no voice	Professionals not listening	14, 40-42, 252-254, 57, 462-464, 569, 446, 193-194, 551, 460, 588-589, 519-523, 448, 196-200, 612, 262-263, 508, 614, 620-621, 637, 600, 751-752, 52-55, 596-597, 379-381, 759, 631-635
	Not heard as a mother By son	432-433, 267, 218-219, 275-276
	By husband	743-745, 732-738, 749-750
	The unspeakable	142, 154, 74
Fear	Fears realised	312, 459-460, 437, 189-191, 268, 269, 401-402, 555-556, 428-430, 417-418
	Fear of violence	232-238, 7-10, 555, 203-204, 74-77, 18, 34-35
	Fears dismissed by others	379-381
	Fear of madness	18, 37-38, 203-204, 41
	Fears unvoiced	74
	Fears for son	246-247, 269, 411, 401, 240, 393, 699-700, 185-186, 189-190
Responsibility	Handed to professionals	95-96, 120-122, 588-589, 683, 777, 588-589, 776-778, 504-505, 370-374, 184-185, 21, 120-121
	Assumed by professionals	124-126, 609-612, 620-621, 568, 626, 62, 48-50
	Assumed by mother	688-691, 252, 266, 402-404, 268, 267, 315, 269, 434, 287
	Assumed by family	321, 325-326
	Shared	688-691, 14, 252, 266
	Avoidance of responsibility	26-27, 358-363, 428-430, 453-454, 577-578, 747
	Avoidance via blame	15-16, 164-167, 539, 602-605
	Avoidance because attempts seem futile	551, 548-549

Containment	By systems	2-3, 48-50, 7, 25, 145-146, 185, 120-121, 476-477, 504-505, 381, 124-126, 567, 570, 368-374, 204, 805
	Attempts by family	5, 268, 267-268
	Cruel to be kind	713, 707-708, 785-786, 796-798, 780
	Ineffective	458, 199, 137-139, 459-460, 577-578, 221-222, 434-435, 451, 519, 588-589
	Loss of personal containment when ill/without support	234-238, 428-430, 187-188, 417-418
Powerlessness	No control Oppression by the system	626, 62, 612, 609-610, 462-464, 614, 623-624, 519-523, 446, 576-578, 52-55, 596-597, 602-605
	No control over the illness	267-268
	Trying to do what I can	298-299, 678, 432-435
	Acceptance of inability to change things	682, 552-553, 548-549, 693-695
Uncertainty	Medical Ambiguity of mental state	33, 462-464, 249-250, 657-659, 26-27, 26, 215-222, 487-491, 268, 267, 190, 265-266
	Ambiguity of treatment	97-98, 149, 146, 765-766, 579
	Personal Uncertainty of feeling	3-4, 572-574, 246-247
	Uncertainty of relationship	341, 539-542, 227, 707-713
	Social	235-241, 555, 7-10, 7-8, 401, 699-700
Knowledge of patient	Mother's knowledge	487-491, 721-725, 519-520, 196-200, 186-190, 463-464, 379, 618-619, 683-684, 261-262, 462-464
	Professionals' knowledge seen as superior (hierarchy of	775-776, 778, 463-464, 384-385, 273, 289, 463-464, 373-374, 504-5, 368-

	expertise)	371
	By Mum	610-612, 252-254, 380-382, 611-612, 631-635, 254, 196-200, 609-610
	By the professionals	193-194, 626, 588-589, 462-464
Loss	Of hopes for son	648-650, 643-650, 659-660, 301-303
	Of progress (hopes for son)	312, 572-573, 206-209, 266-267, 206-209
	Of normality/perspective	82-83, 62-69, 65, 81, 80-81
	Of role	693, 18, 34-35
	Of relationship	225
	Of time	772, 765-766
	Futility	209
Impact on relationship	Relationship with family	341, 522-523, 548, 321, 547, 538-539, 530, 544, 536, 529, 525-526, 534
	Relationship with professionals	626, 620-621, 623-624, 611-612
	Relationship with son	707-708, 274-276, 283, 274
	Subordinate to his welfare	707-708, 707-713, 432, 348, 272
Optimism-hope	Seeing the positives	144-146, 210-211, 212, 764-765, 402-404, 476-477, 126, 572-574
	Hope with finding a solution	25-26, 109-110, 95-96
	False hope	48-50, 114-115, 95-96, 688-691
	Realistic hope	149, 721-725, 779-780, 572-574
Coping	Coping attitude	680-682, 721-725
	Strategies	
	Friends:	298-299, 168-171
	Humour:	276
Honesty (with friends)	156-160	
What would have helped	667-668, 668-69, 673, 666, 672-674	
Having a voice	With professionals	261-262, 618-619
	Lip service	683, 448-449, 380
	With son	278, 267, 277

Appendix 15: Themes with quotes 1st coding (Clare)

Containment

By systems

- When he was first admitted it was actually a huge relief because it had been quite a confused period, he was all over the place (2-3)
- Now we know what it is we can deal with it (48-50) (pre admission)
- I knew he'd be safe (7)
- as soon as they actually put a label on it (25)
- treatment second to none... a turning point (145-146) (Broadmoor)
- he was being very well watched over (185)
- he's not going to be able to... come out and do his own thing, there's always going to be someone keeping an eye on him. (120-121)
- He doesn't have the rights (under S41) and I think that's a good thing (476-477)
- I was very grateful that he was supposed to be having this supervision, and that they would be doing regular tests to make sure that he wasn't taking drugs (504-505)
- They will be watching him (381)
- fine as long as you're taking your medication and you're well, we'll leave you alone, but if you don't then we're on top of you and we'll have you back. And I thought that was a good thing (124-126)
- The police got involved and at that point... (567) (*parallel to pre admission*)
- We've held on as long as we can (570)
- They knew by his results and his behaviour that he wasn't taking it...and that was enormously reassuring to me because...they can tell (368-374)
- I was hugely relieved when he Was recalled (204)
- I think he should be protected (805)

Attempts by family

- we can't contain him (5) (*pre admission*)
- I couldn't let it go once I saw him sliding (268) (*pre recall*)
- I wanted to try and get him to pull back himself (267-268)

Cruel to be kind

- That's what he needs (713) (*condition of no alcohol*)
- I would find it difficult to say that in front of him because I know he would be so cross with me, but I think it would be the right thing for him and I would say it (707-708) (*ask for no alcohol condition*)
- What's the point of putting him in a position where he can backslide (785-786)
- I'd like that to be made impossible...which would obviously affect him (796-798) (*stop medication, start drinking*)
- Freedom with restrictions so he wouldn't have the chance to backslide (780)

Ineffective

- rights of the individual, you can't impose this, that, and the other (458)
- We can't do anything until we have the proof (199)
- wasn't strong enough to hold him (137-139) (TGU security 1st admission)
- He was completely let down by the people looking after him (459-460) (conditional discharge)
- Why does it have to get so bad before anybody'll do anything (577-578) (*parallel to pre admission*)
- he was gone too far (221-222)
- Bought him some clothes but it didn't last long (434-435)
- Very disappointed with the supervision (451)
- We can't recall him on your say so (519)
- If they'd taken the problems seriously (588-589) (*parallel to pre admission*)

Loss of personal containment when ill/without support

- Full of anger, getting into fights, a big strong boy, I was very scared (234-238) (*pre admission*)
- Once he was on his own (his self-care went) (428-430)
- He's so disorganised and once it starts to slip he stops seeing the purpose of it (187-188)
- his personal hygiene was completely gone; his clothes were in rags (417-418)

Coping

Attitude

- What's the worst that can happen... if that happens we just cope with it (680-682)
- I know he'd still be disorganised...but he could manage alright (721-725)

Strategies

Friends:

- Supportive & sympathetic but nothing they could do (298-299)
- My friends were tremendously sympathetic and supportive (168-171)

Humour:

- He thinks I'm stupid because I've been taken in by you all (*laughs*) (276)

Honesty (with friends)

- I always made a point of trying to be open ...because that way I got much more support (156-160)

What would have helped

Feeling heard/taken seriously:

- We're listening to your worries and we will keep a closer watch on him and we will assess it for ourselves but taking on board what you are saying (667-668)
- Assess for ourselves but take on board what you are saying (668-669, 673)
- If I'd been taken seriously (666)

- If they'd taken me more seriously, listen to what I was saying, and not necessarily accept it without looking into it themselves but (672-674)

Fear

Fears realised

- (Hopes) dashed again and again and again (312)
- He was completely let down (459-460)
- when I cleared out the flat it was unbelievable (437)
- My worry that he would not take his medication, and that the whole thing would backslide, which is what ultimately happened (189-191)
- Once I saw him sliding (268)
- Even if it does lead to him being recalled (269)
- He did get himself into a terrible, terrible mess (401-402)
- I imagined it would end up in a fight...which is what happened (555-556)
- Once he was on his own... he wasn't eating, he wasn't washing his clothes, he wasn't washing himself (428-430)
- Terrible state, hygiene completely gone, clothes in rags (417-418)

Fear of violence

- I didn't feel personally intimidated by him... but I was very scared because he...was full of anger...getting into fights, so I was scared for him but I was also scared...of what he might do to other people (232-238)
- Danger of him seriously harming others or self (7-10)
- I imagined that it would all end up in a fight (555)
- I saw again that same awful look in his face that I saw when he was 17 and I was really scared again (203-204) (*conditional discharge: parallel to pre admission*)
- Scared again (202-204) (*conditional discharge: parallel to pre admission*)
- That same awful look (203) (*conditional discharge: parallel to pre admission*)

- V was very scared for a long time (74)
- she has a phobia of knives even now (76)
- used to barricade her bedroom door (75)
- just terrified (77) (*daughter*)
- Frightened of own child (18, 34-35)

Fears dismissed by others

- The main worry I voiced...that's my concern and they said no, no, no (379-381)

Fear of madness

- Frightened of madness (18, 37-38)
- I saw again that same awful look in his face that I saw when he was 17 and I was really scared again (203-204) (*conditional discharge: parallel to pre admission*)
- Scared again (202-204) (*conditional discharge: parallel to pre admission*)
- That same awful look (203) (*conditional discharge: parallel to pre admission*)
- He'd say all the right things and he came across as being perfectly rational (41) (*pre admission*)

Fears unvoiced

- V hadn't told me, she told me years later (74) (*pre admission*)

Fears for son

- Fear (heightened attention to danger signs): if the phone ever rang late at night or whenever I heard a police siren, at the back of my mind it was always, you know, is that something to do with (*name of son*)? (246-247)
- I always worried about him (269)
- I was very worried about the people he was mixing with and influences (411)
- I was worried about whether he's be able to cope financially (401)

- What might happen to him (240)
- I was scared (393) (*son not taking medication*)
- One of my worries ... that he would stop taking his medication and the other thing was whether he would go out drinking (699-700)
- My fear all the way through when discharge started to be talked about was that he wouldn't keep his medication up (185-186)
- That was my worry that he would not take his medication (189-190)

Having a voice

With professionals

- If you thought he was not taking his medication would you say? (261-262) (*pre discharge*)
- It helps us...to know your views (618-619) (*after recall*)

Lip service

- Kept ringing up (683) (*although ignored*)
- come along to the meetings...when it came to listening to what I was saying, just not interested (448-449)
- They said did I have any concerns? (380)

With son

- I have always been honest with him, never pretended to him (278)
- I wanted to try so I talked to him (267)
- that's your opinion, you're entitled (277) (*son talking to mother*)

Having no voice

Professionals not listening

- An assessment, which I'd been asking for, for ages (14) (*pre admission*)

- He'd go along to see a doctor...and he'd say all the right things, and he came across as being perfectly rational.(40-42) (*pre admission*)
- I've always gone to his review meetings...but they would never...I'm not the professional so I don't know (252-254)
- Nobody took what I was saying seriously (57)
- Like going back to when he was seventeen and I was saying to the doctors (462-464)
- As if I'd been saying you mustn't recall him (569)
- frustrating...what's the point of involving me (446)
- I voiced that (fears) frequently and I was told absolutely, categorically this could not happen (193-194)
- I was trying to tell people (551)
- I wasn't getting anywhere telling them (460)
- If they'd taken the problems seriously (588-589)
- We can't recall him on your say so...I know he's taking it; so frustrating, worrying (519-523)
- When it came to listening to what I was saying just really not interested (448)
- I spent six months...telling the people who were supposed to be supervising ..he's not taking his medication, I know he's not, I just know it.well we can't do anything until we have the proof (196-200)
- Go away (612)
- I said and nobody would listen (262-263)
- I told them that, I told them (508) (*but ignored*)
- Sidelined (614)
- They were tolerating me and I was a bit of a nuisance (620-621)
- They weren't taking any notice (637)
- Just a mother (600)

- I was considered this fussy, over-reactive, neurotic mother (751-752)
- It was really once the police were involved and he got on the wrong side of the law that, and the judge said 'right, you know you've got to do something'. And that was when he started getting the help he needed. Not until he got on the wrong side of the law. (52-55)
- Nobody would take it seriously until he got into trouble (596-597)
- The main worry I voiced...that's my concern and they said no, no, no (379-381)
- bit like a young lad going up to university (759) (*minimising her concerns, echoes husband pre admission*)
- they'd told them...I'd told them (631-635) (*staff 'lower' in hierarchy also ignored*)

Not heard as a mother

By son

- he wasn't going to pay any attention to me (432-433)
- I wanted to try so I talked to him (267)
- I'd talk to him ...he'd say No, it's alright (218-219)
- He thinks I'm stupid because I've been taken in by you all (275-276)

By husband

- he needs to go in the army, on an outward bound course, then he'll be alright (743-745) (*minimising her fears, echoed later by professionals*)
- I wanted to take it seriously... N (husband's) attitude to all these bizarre and dreadful things that (*name of son*) did was 'well boys will be boys...it's just a bit of high spirits' (732-738)
- He'd say to (*name of son*) 'oh take no notice of your mother, she's just fussing (749-750)

The unspeakable

- couldn't say the word (142) (Broadmoor)
- I'm not going to be able to tell anyone (154)

- *(daughter)* hadn't told me, she told me years later (74) *(fears as a child about her brother)*

Impact on relationship

Relationship with family

- And it wasn't until he'd gone, I began to think, crikey, you know is this how everybody lives, is this, is this normal? And I think it actually took its toll (67-68)
- it did have such an effect on the whole family (71-72)
- Well it did have a huge impact because so much time was taken up with trying to deal with his problems and just the normality of life wasn't there. He was always; he was very, very disruptive and so there just wasn't the normal, quiet, run of the mill, you know trundling along of family life (80-83)
- Gradual shutting off from us (341)
- We were all very, very worried (522-523)
- They were all walking away from it (548)
- He's going to our responsibility (321)
- I've had enough (547) *(brother, pre recall)*
- P got cross with him (538-539) *(brother, pre recall)*
- And I think it actually took its toll, certainly on *(daughter)* because she was the next one down and being a girl, it took its toll on her more than any of them (68-69)
- *(daughter)* was very scared for a long time, which I didn't realise. She hadn't told me. But she told me years later that she used to barricade her bedroom door when she was in there because she was scared of *(name of son)* and she does have a phobia of knives even now. Because *(name of son)* used to play around with knives menacingly. She was just terrified and I didn't realise for years (74-78)
- didn't want to see him again, couldn't face it (530) *(daughter pre recall)*
- cut herself off completely (544) *(daughter pre recall)*
- she couldn't cope with it (536) *(daughter pre recall)*

- She was knocked sideways (529) (*daughter pre recall*)
- (*daughter*) was totally distraught because it had taken her a number of years to rebuild some sort of relationship with (*name of son*) (525-526) (*daughter pre recall*)
- she does now; she didn't see him again in all that time (534) (*daughter after recall*)

Relationship with professionals

- I didn't feel in any way part of his care team (626)
- They were tolerating me and I was a bit of a nuisance (620-621)
-
- It's (*name of son*)'s mother again, you deal with her (623-624)
- We know what we're doing and go away (611-612)

Relationship with son

- He would be angry with me (707-708) (*for disagreeing; asking for controls to be imposed*)
- He's been cross with me, thinks I'm stupid... taken in by you all (274-276)
- He's perceived me as being on the wrong side (283)
- He doesn't hold it against me (274)
- I was actually frightened of him. He was scaring me because he was big, he was just mad (18)
- they sent (*ex-husband*) and me to family therapy, and, you know, I couldn't see any end to it (32-33)
- I actually, actually was scared of him. And that's a horrible experience to be scared of your own child. And I'd never been frightened of him until that point. But he was just beyond me (34-35)
- I'd been struggling since he was at primary school (47)
- The teenage years were just a nightmare, a complete nightmare (51)
- it was a nightmare for years and years and years. And it wasn't actually until he'd gone, when he was 17 that I realised, what an extraordinary effect, what

we'd been living with. It really wasn't until he, because you slip into these things gradually don't you (63-65)

Relationship with son subordinate to his welfare

- I would find it difficult to say that in front of him because I know he would be so cross with me, but I think it would be the right thing for him and I would say it (707-708) (*ask for no alcohol condition*)
- I would say it and it's possible that he could...say...don't come to my Tribunals...I would still say it because that's...what he needs (707-713)
- Never torn between a relationship with him or his welfare (432)
- No relationship if not well (348)
- that has worried me and I have had to face that on a number of occasions (272) (*if she told professionals*)

Knowledge of patient

Mother's knowledge

- he would say to me 'I'm fine, nothing wrong with me (487-491)
- I know he'd still be disorganised...but he could manage alright (721-725)
- I know he's taking it (519-520) (*drugs*)
- He's not taking his medication I know it, I just know it, I know he's not well (196-200)
- (*name of son*) is so disorganised even now,...once it starts to slip he stops seeing the purpose of it (*medication*) (186-190)
- I'm not a doctor but I know he's not well (463-464)
- That was again the main worry I voiced (379)
- It helps us...to know your views (618-619) (*post recall*)
- He's really in a bad way (683-684)
- If you thought he was not taking his medication would you say? (261-262) (*pre conditional discharge*)

- Like going back to when he was seventeen and I was saying to the doctors (462-464)

Professionals' knowledge seen as superior (hierarchy of expertise)

By Mum

- he's the expert and I'm not... that's a medical decision (775-776)
- I trust his (*doctor's*) judgement (778)
- I'm not a doctor but I know he's not well (463-464)
- They should have been able to tell (384-385)
- I think they're right (273)
- I can't, I'm not medical (289)
- I'm not a doctor, I don't know but he's not well (463-464)
- Reassuring... Because... they can tell (373-374)
- I was very, very grateful that he was supposed to be having supervision, and that they would be doing regular tests to make sure he wasn't taking drugs (504-505)
- They said he wasn't taking it, they knew by results and his behaviour (368-371)

By the professionals

- we are his support workers and yes, you're his mother and obviously you're concerned but it really isn't any of your business (610-612)
- I've always been involved... but they would never, I'm not the professional so I don't know (252-254)
- no, no, no, they will be watching him; having tests (380-382) (*dismissing her fears*)
- We know what we're doing (611-612)
- they'd told them... I'd told them (631-635) (*professionals assume greater knowledge of patient than support staff: hierarchy of 'expertise'*)
- I'm not the professional so I don't know (254)

- We need proof (196-200) (*for what she had told them*)
- This isn't any of your business (609-610)
- We will know if he doesn't take his medication (193-194)
- I didn't feel in any way part of his care team (626)
- If they'd taken the problems seriously (588-589)
- Like going back to when he was seventeen and I was saying to the doctors (462-464)

Loss

Of hopes for son

- Death of all the hopes you had for them, the hopes and expectations and you realise that's not going to happen (648-650)
- time of grieving where you come to realise that your child is never going to be (643-650)
- When I saw him backsliding, I knew... a lot of coming to terms with it then and accepting (659-660)
- It's an immense, it's very sad, huge, huge sadness ...you think back to this baby and innocent child and you have such high hopes for them (301-303)

Of progress (hopes for son)

- Hopes dashed again and again and again (312) (*conditional discharge*)
- I'm heartbroken that it's come to this (572-573) (*recall*)
- It broke my heart because he'd got this flat...he was losing that and it was all going to be thrown away (206-209) (*recall*)
- I didn't want to precipitate him into being recalled because he had such a lot to lose (266-267)
- Broke my heart...he was losing that and it was all going to be thrown away (206-209)

Of normality/perspective

- there just wasn't the normal, quiet, run of the mill, trundling along of family life (82,83) (*pre admission*)
- It wasn't until he was gone...is this normal (62-69) (*pre admission*)
- slip into these things gradually (65)
- the normality of life wasn't there (81)
- so much time was taken up with trying to deal with his problems (80-81)

Of role

- I had to let that go over the years (693) (*control*)
- Frightened of own child (18, 34-35) (*pre admission*)

Of relationship

- Gone back into his own world (225) (*conditional discharge*)
- we were irrelevant (225) (*conditional discharge*)

Of time

- Shame he's had to spend so long back at (*unit*) (772) (*recall*)
- The work of a moment to get recalled and a couple of years to ...get out again (765-766)

Futility

- It was all so unnecessary (209)

Optimism / Hope

Seeing the positives

- was really hard...a difficult time, but... a turning point (144-146) (*Broadmoor*)
- there was purpose in it in that he has learned a lot from it (210-211) (*recall*)

- tremendous leap forward (212)
- he's learned to toe the line otherwise people have the power to recall (764-765)
- sorted out his financial difficulties (402-404) (*recall*)
- He doesn't have the rights (*under S41*) ...good thing (476-477)
- I thought that was a good thing (126) (*restrictions*)
- I'm heartbroken but really pleased (572-574)

Hope with finding a solution

- we can deal with this (25-26) (*with diagnosis/label*)
- now they know what it is they can give him the right medicines, he can live a normal life, it'll be fine (109-110)
- you'd be able to look at the problem, diagnose it and put it right, like a car (95-96)

False hope

- Now we know what it is we can deal with it' (48-50) (*Different diagnoses pre admission*)
- he'd be stabilised... go to college, get a job, become normal and stable (114-115)
- you'd be able to look at the problem, diagnose it and put it right, like a car (95-96)
- I felt much more in control then... I can do this, I can make things happen...I'll sort him out, get his life in order (688-691) (*pre admission*)

Realistic hope

- a slow climb (149)
- I know he'd still be disorganised...but he could manage alright (721-725)
- More independence and freedom with restrictions so he wouldn't have the chance (*of backsliding*)(779-780)
- I'm heartbroken, but really pleased (572-574) (*recall*)

Powerlessness

Powerlessness as a process (could be not being in control, helpless, oppression; or could be acceptance of an inability to change the situation)

No control

Oppression by the system

- I didn't feel in any way part of his care team (626)
- We are the experts, we know (62)
- we know what we're doing and go away (612)
- This isn't any of your business (609-610)
- Like going back to when he was seventeen and I was saying to the doctors (462-464)
- Sidelined (614)
- It's (*name of son*)'s mother again, you deal with her (623-624)
- We can't recall him on your say so...it was so frustrating, we were all very, very worried (519-523)
- What's the point of involving me (446)
- This is exactly what I felt way back when he was seventeen, that much earlier intervention would have, you know, why does it have to get so bad before anybody'll do anything (576-578)
- It was really once the police were involved and he got on the wrong side of the law that, and the judge said 'right, you know you've got to do something'. And that was when he started getting the help he needed. Not until he got on the wrong side of the law. (52-55) (*indicates power hierarchy*)
- Nobody would take it seriously until he got into trouble (596-597)
- I was the one with the problems (602-605) (*blamed*)

No control over the illness

- I wanted to try and get him to pull back himself (267-268)

Trying to do what I can

- Supportive & sympathetic but nothing they could do (298-299)

- I can't do anything else, I'm doing what I can (678)
- There's nothing you can do... he wasn't going to pay any attention to me. I talked to him and once or twice I took him off to Tesco's and bought him some clothes but it didn't last long or they disappeared (432-435)

Acceptance of inability to change things

- Gave up idea of making it right because I knew I couldn't (682)
- There was nothing I could do, in the end we just all had this fatalistic, whatever happens will happen (552-553)
- They were all walking away from it, there was nothing they could do (548-549)
- I definitely had to let that go over the years, definitely ended up feeling out of control...which is fair enough, I mean the thing is nobody is really in control in a situation like *(name of son)*'s (693-695)

Responsibility

Handed to professionals

- you'd be able to look at the problem, diagnose it and put it right, like a car (95-96)
- Someone keeping an eye on him (120-122)
- If they'd taken the problems seriously (588-589) (conditional discharge parallel to pre admission)
- Have you seen *(name of son)*? (683)
- I don't have the expertise to make those judgements (777)
- If they'd taken the problems seriously (588-589)
- I would concede that ...I wouldn't want to fight for what I wanted over something that Dr X. felt was better because I trust his judgement (776-778)
- Grateful he was supposed to be having this supervision and that they would be doing regular tests to make sure that he wasn't taking drugs (504-505)
- Reassuring that they can tell (370-374) (*not taking meds*)

- I was very pleased...he was still being very well watched over (184-185) (*initial discharge placement*)
- they could see the cracks (21) (*on/pre admission*)
- Can't come out and then do his own thing (120-121)

Assumed by professionals

- if you don't we're on top of you and have you back (124-126)
- This really isn't your business (609-612)
- they were tolerating me and I was a bit of a nuisance (620-621)
- We're going to have to (recall) (568)
- I didn't feel I was in any way part of his care team (626)
- We are the experts, we know (62)
- Now we know what it is we can deal with it (48-50) (*pre admission*)

Assumed by mother

- I felt much more in control then even though I wasn't...I can make things happen...and once they give him the right medication...I'll sort him out, get his life in order (688-691)
- Always gone to his review meetings and been involved (252)
- I didn't want to precipitate him being recalled (266)
- One benefit of him being recalled, he handed over his bankcard to me and gradually...I eliminated his overdraft (402-404)
- I couldn't let it go (268)
- I wanted to try and get him to pull back (267)
- Will always worry (315)
- Even if it does lead to him being recalled (269)
- I bought him some clothes (434)
- Do what's best for your child (287)

Assumed by family

- He's going to be our responsibility (321)
- we'll always worry about him, always have to be involved (325-326)

Shared

- I felt much more in control then even though I wasn't...I can make things happen...and once they give him the right medication...I'll sort him out, get his life in order (688-691)
- I'd been asking for (*an assessment*) for ages (14)
- Always gone to his review meetings and been involved (252)
- I didn't want to precipitate him being recalled (266)

Avoidance of responsibility

- He's not really our bag...we don't know quite what this is (26-27) (*pre admission*)
- Why does it have to get so bad before anybody'll do anything (577-578)
- overworked, don't have time, but (453-454) (*professionals*)
- Once he was on his own... he wasn't... eating... washing, you could smell him coming up the road (428-430)
- I don't think he liked the people that were there, don't think he was the right man for the job...didn't put himself out (358-363) (*professional at conditional discharge placement*)
- We never had a united... (747) (*husband unsupportive*)

Avoidance via blame

- They kept telling me that it was my problem as much as his (15-16)
- I was the one with the problems (602-605)
- my family ...are critical ...this wouldn't have happened to them (164-167)
- you've got to pull yourself together (539) (*brother's attitude pre recall*)

Avoidance because attempts seem futile

- There was nothing I could do (551)
- They were all just walking away from it, there was nothing they could do (548-549) (*family before recall*)

Uncertainty

Medical

Ambiguity of mental state

- No end to it (33) (*pre admission*)
- Like going back to when he was seventeen and I was saying to the doctors (462-464) (*conditional discharge*)
- first inklings that things were not right (249-250) (*conditional discharge*)
- The next step...go along gradually, get better and better...backsliding (657-659)
- We don't know what this is (26-27) (*pre admission*)
- he's not our bag (26) (*pre admission*)
- The first few danger signs I tried to rationalise...think perhaps I'm imagining it and I'm sure he's alright...he'd seem to be OK...I used to talk to him...he would reassure me... put my mind at rest (215-222)
- Everything begins to slip (487-491)
- Couldn't let it go once I saw him sliding (268)
- I wanted to try and get him to pull back (267)
- The whole thing would backslide (190)
- When I first began to suspect (265-266)

Ambiguity of treatment

- more complicated and ...considerably longer than I'd expected (97-98)
- slow climb (149)
- turning point (146)

- The work of a moment to get recalled and a couple of years to ...get out again (765-766)
- It's a much longer trek back (579)

Personal

Uncertainty of feeling

- Confused, all over the place (3-4)
- I'm heartbroken, but really pleased (572-574) (*ambivalence of feeling*)
- if the phone ever rang late at night or whenever I heard a police siren, at the back of my mind it was always, you know, is that something to do with (*name of son*) (246-247)

Uncertainty of relationship

- Gradual shutting off from us (341)
- not able to make any sense of it... means nothing to him (539-542) (*conditional discharge when ill*)
- He couldn't seem to take in what I was saying (227)
- it's possible that he could ... say ..don't come to my Tribunals...I would still say it because that's...what he needs (707-713)

Social

- scared...of what he might do to other people...and what might happen to him (235-241)
- I imagined that it would all end up in a fight (555)
- Danger of him seriously harming others or self (7-10)
- nobody else would be in danger...there was a real danger of him hurting someone (7-8)
- I was worried about whether he's be able to cope financially (401)
- one of my worries ... that he would stop taking his medication and the other thing was whether he would go out drinking (699-700)

Appendix 16: Themes by phase (Clare)

Preadmission

- Scary, frightened of madness in son and what he could do to himself or others
- Not knowing what to do, what 'it' is (uncertainty)
- No end to it, no solution, nightmare
- Not listened to / take seriously by the experts (it's *her* problem)
- The effect on her and her family (e.g. sister terrified_ - eats up time, family life, normality)
- Only gets help *after* something happens
- She can look after him / feels she will be able to sort him out (unlike when he is conditionally discharged)

Admission

- Huge relief; he is safe, contained; has a label so can be treated (a solution is found so the nightmare ends)
- Hope; he will be normal and all OK, but loss of hope when TGU could not contain him
- Restriction order seen positively, he will be contained
- Coping when hope lost- friends' support

Conditional discharge

- Pleased (starts off hoping that he will continue to improve, linked to him still being contained) reassured that the professionals are monitoring him
- Fears (as well at start) because she knows the pitfalls he is likely to fall into (e.g. non compliance with meds, drinking, financial chaos); fear when he moves that he won't be monitored (contained) as well as previously
- Gradual loss of son: tries to think it's OK but gradual realisation that it's not OK; he can't see his decline when she can
- Tries to help him herself (doing what I can/ responsibility) but too much on her own, she can't actually *do* anything; powerlessness felt by whole family
- She tries to get help but ignored
- Loss (death) of hopes for son when she sees him backslide (she had to come to terms with this-acceptance) / loss of relationship with him as son and brother / he lost what he had achieved
- His welfare more important than her relationship with him
↓
- Not listened to: the 'experts' think they know better; 'just a mother'
↓

- Scared again at what he might do/ what might happen to him (whole family worried)
- Loss of hopes



- Only gets help *after* something happens
- Relief at recall

(The difference between conditional discharge and when he was first admitted is that she felt hope and relief on admission and hope and fear on conditional discharge)

Recall

- Loss of what he had achieved in conditional discharge (broke heart/unnecessary)
- Hope; he has learned from the experience, leap forward
- She can sort him out (financially) again
- Takes a long time to get out again
- Trust the 'experts'

(The difference between recall and when he was first admitted is that she felt hope and relief on admission, but loss and relief when he was recalled. Both are associated with a feeling of 'why did it have to get to this?' Another difference is that at recall they *know* what the problem is, so by implication should have acted earlier)

Future

- Feels responsible for son?
- Worry about son; he might stop meds or drink. Would be reassured by containment of son (if no alcohol/ compliance with meds).
- Hope (more realistic?) she had hopes he would be cured on admission, then that he would continue to improve when conditionally discharged, but when her hopes died, she had a process of acceptance and then formed more realistic hopes for the future, and the family accept that they will always worry about him and feel responsible for him
- His welfare paramount.

What would have helped: conditional discharge

Being taken seriously and listened to (not necessarily accepting without assessing for themselves)

What helped: conditional discharge

Doing what I can

Accepting that she will just have to cope with whatever happens

Processes

Fear, relief, hope and loss

Hope associated with relief on admission; she had hopes he would be cured on admission and relief that he was contained

Hope and fear at conditional discharge; she hoped that he would continue to improve and feared that he might default on meds and drink too much
Hopes died and she had to come to acceptance of loss of hope

Loss associated with relief at recall; loss of hopes, achievements, relief that he was contained again.

Loss of hopes leads to more realistic hopes for the future
The family accept that they will always worry about him and feel responsible for him

Admission and recall similar: 'why did it have to get to this?' / at recall they *know* what the problem is, so by implication should have acted earlier

The way she feels she is perceived as a mother

Pre admission she is 'just a mother', considered as neurotic and having problems (because of problematic relationship with husband)

Conditional discharge she is sidelined- son is adult and she is irrelevant, ignored, not part of team

Recall she is seen as a resource

Feeling in control

Started off thinking she could sort things out once they knew what it was but over the years ended up feeling totally out of control ('no one is in control')

Appendix 17: Example of 2nd coding of interview (Clare)

Themes from 1 st analysis	Transcript P1 (Clare; lines 184 - 254)	2 nd coding themes
<p>Containment by others / system, responsibility handed to professionals. Fears for son Mother's knowledge of son Personal containment lost when ill / no support.</p> <p>Uncertainty of mental state Fears for son realised</p> <p>Having no voice; professionals dismiss concerns. Professionals assume their</p>	<p>C I was really very, very, very pleased about that because he was still being very well watched over at that point. My fear all the way through when discharge started to be talked about was that he wouldn't keep his medication up. Now this was partly because Michael is so disorganised, even now. He is so disorganised and once it starts to slip then he stops seeing the purpose of it, and he has never, at that point he didn't really accept he had schizophrenia. He said, 'well they say I have, they say I need it'. So, so that was my worry, that he would not take his medication. And that the whole thing would backslide, which is what ultimately happened.</p> <p>R mm</p> <p>C And I voiced that frequently. And I was told absolutely, categorically,</p>	<p>Emotional impact- pleasure at discharge (still contained) Accompanied by fear prior to conditional discharge Responsibility handed to professionals who will watch over son</p>

<p>knowledge is superior than mother's</p> <p>Promised containment ineffective</p> <p>Professionals assume their knowledge is superior than mother's Mother knows son Not heard by professionals/ having no 'voice'</p> <p>Fear of violence / madness in son Containment by forensic system of son and what is in him.</p>	<p>this could not happen. He was going to be supervised. 'We will know if he doesn't take his medication', but...</p> <p>R It didn't work out</p> <p>C It didn't work out. I spent six months at least from Christmas until the time he was recalled in the middle of July I spent telling the people who were supposed to be supervising him that he wasn't- that 'he's not taking his medication, I know he's not, I just know it'. And they 'well, we can't do anything, you know, until we have the proof'. I said 'but, you know, I know he's not taking it, I know he's not well'</p> <p>R mm</p> <p>C And before, just before he was recalled, if this isn't, sort of jumping ahead too much, I saw again, that same awful look in his face that I saw when he was seventeen, and I was really scared again at that point, and I was hugely relieved when he was recalled.</p> <p>R Yeah</p>	<p>The professionals , the experts 'know', assume expertise</p> <p>Impenetrable system: she's banging on a door that won't open; shut door; not being listened to by professionals</p> <p>Collateral damage / Emotional impact: she was scared, and relieved when he was recalled; process of fear-relief</p>
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<p>Loss of progress / hopes for son</p> <p>Loss of hope - futility</p> <p>Seeing the positives; optimism, and hope (process)</p> <p>Uncertainty: ambiguity of mental state</p>	<p>C Although it broke my heart, because he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful. And I, just the thought that he was losing that and it was all going to be thrown away, that (...) and it was all so unnecessary, or it seemed it to me, although now, at this point I think there was a purpose in it, in that he has learned a lot from it, and he, he does now actually accept that he is schizophrenic, which is a tremendous leap forward I think.</p> <p>R Yeah. So when, when was the first time that you thought that there was a bit of a slip, what did that make you feel?</p> <p>C Well, I suppose, I suppose the first few danger signs I tried to rationalise, you know, and think perhaps I'm imagining it and I'm sure he's all right, and he'd come back and he'd seem to be OK. I used to talk to him about it, because he was drinking you see which was bad news, and I'd talk to him about it and he'd say, you know when he was first beginning to backslide, he would reassure me and say, 'No, no, it's all</p>	<p>Collateral damage: Loss and grief, loss of what he had achieved</p> <p>Responsibility, she was doing what she could to help her son</p> <p>Loss felt for son</p> <p>Implicit blame of team / son for his deterioration</p> <p>Hope and optimism regained for what she perceives son has learned</p> <p>Responsibility: giving son autonomy, but anxious about his ability to manage on his own and vigilant to signs of deterioration</p> <p>Emotional impact: hoping that signs of deterioration are a 'one off'</p>
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<p>Not 'heard' as a mother, no communication / voice with son Containment ineffective</p>	<p>right Mum, I know, OK, yes I've been drinking a bit much and I'm not going to', and, and put my mind at rest. But then later on, he, you know he just went completely, withdrew into himself, didn't even bother trying to (...) but he was gone too far then</p> <p>R Did he withdraw from you and from family?</p>	<p>Loss- of relationship with son</p>
<p>Loss of relationship / communication with son Uncertainty of relationship</p>	<p>C Um, not physically, he still kept coming round, but within himself he was, you know you could see he had gone back into his own world. We were irrelevant and when I drove him back to (<i>discharge placement</i>) he barely spoke to me; he was just there in the car. And if I spoke to him, he didn't, he couldn't seem to take in what I was saying, however mundane it was. I mean he was really, really ill again, really bad.</p> <p>R So you were scared</p> <p>C Yeah</p> <p>R About what, about what....</p>	<p>Loss of her relationship with her son Responsibility: she still does what she can</p>

<p>Fear for son Fear of actual violence Loss of personal containment when ill</p>	<p>C I didn't personally feel physically intimidated by him, I mean he didn't turn on me, but I was very scared because he had that, he said he was full of anger, and he was getting into fights so I was scared for him but I was also scared because he's a big strong boy and I was very scared</p>	<p>Collateral damage scared ? Trauma Process of fear, when things have deteriorated; fear of what he has become, what he is capable of</p>
<p>Fear of potential violence? / actions towards others Uncertainty of son's actions</p>	<p>R About what he might do?</p> <p>C Of what might, yeah, what he might do to other people</p>	<p>Collateral damage: fear</p>
<p>Fear for son's safety</p>	<p>R Yeah</p> <p>C And you know, what might happen to him, because the people he was mixing with, you know there were knives, and all sorts of nasty things</p> <p>R So you'd drop him off [<i>to discharge placement</i>] and not know</p> <p>C Yeah</p>	<p>Collateral damage: fear</p>

<p>Fear for son Uncertainty Hypervigilance to threat</p>	<p>R what was going to happen? Did you ever sort of picture in your head what might; how far it might go?</p> <p>C Not so much that, but I, if the phone ever rang late at night, or whenever I heard a police siren, at the back of mind it was always, you know, is that something to do with Michael?</p>	<p>Collateral damage: anxiety about son and what might have happened</p>
<p>Uncertainty; ambiguity of mental state</p>	<p>R Yeah, was that, how long did that go on for?</p> <p>C Well certainly, probably the best part of a year actually, from the first inklings that things were, were not right.</p>	
<p>Responsibility assumed by mother Responsibility shared with professionals Feels that professionals assume their expertise is superior Having no voice? Professionals not listening?</p>	<p>R And you tried to talk to him about it</p> <p>C Yeah, initially. And I've always gone to his review meetings and been involved because he's always been willing for me to be, and um, but they would never, never, you know, just like when he was a teenager, I'm not the professional, so I don't know</p>	<p>Not treated as part of the team; Expert system. Professionals assume superior expertise, her knowledge is marginalised</p>

Appendix 18: table of themes from 2nd coding (Clare)

Super-ordinate theme	Theme	Phase	Quotes
Collateral damage	Process of fear-hope-loss	Preadmission	2-3, 6-10, 17-19, 24-26, 33-38, 49-51
		Admission	95-98, 109-110, 113-115, 120-126, 137-146, 153-154
		Conditional discharge	184-191, 224-228, 232-247, 265-269, 301-305, 312, 339-348, 370-374, 378-388, 393-402, 411, 417-418, 428-435, 504-505, 525-530, 536, 552-553, 643-662, 678-684, 699-700
		Recall	202-212, 572-574, 718-725
	Identity	Preadmission	34-35, 67-68, 80-83, 600-605, 749-752
		Admission	137-144, 153-156
		Conditional discharge	609-612, 618-624, 672-673
		Recall	618-619
		Future	314-316, 325-326
	Trauma	Preadmission	17-19, 33-38, 51, 63-64, 74-78, 731-732, 738-742
		Admission	137-142, 153-156
		Conditional discharge	202-204, 234-240, 246-247, 525-536, 544
	Specialist service requires specialist help	Admission	137-142, 153-156

An impenetrable system	Shut door	Preadmission	3-5, 12-16, 24-27, 30-33, 40-42, 47-55, 57, 588-589, 592-598
		Admission	24-27
		Conditional discharge	448-449, 459-460, 196-200, 462-464, 518-522, 551-553, 609-614, 635-637, 666-676, 682-684
		Recall	578-584
	Engulfed	Admission	96-98
		Conditional discharge	609-614, 623-624
		Recall	763-766, 772
	Open door	Admission	168-171
		Conditional discharge	298-299
Recall		618-619	
Responsibility	Parental- doing what I can	Preadmission	47-50, 80-81, 688-691
		Conditional discharge	206-208, 265-269, 426-442, 678-684
		Recall	402-404
		Future	314-326
		Legal superiority	52-54, 596-598
	Handed to professionals	Admission	95-96, 109-110, 120-126, 184-185, 287-291
		Conditional discharge	368-378, 504-505
		Recall	774-778
	Uncertainty as to who holds responsibility	Conditional discharge	252-254, 266-267, 380-382, 448-449, 518-522, 567-570, 616-621, 633-637, 666-676

	Blaming and feeling blamed	Preadmission	57, 588-589, 596-597, 602-605, 749-752
		Admission	137-140, 164-167
		Conditional discharge	208-210, 261-263, 384-385, 451, 459-460, 568-569, 666-676
		Recall	273-277
		Positive aspects	145-149, 210-212
	Infantilisation vs. autonomy / progress to independence	Preadmission	688-691
		Conditional discharge	215-220, 265-269, 483-488, 539-542, 546-547
		Recall	314-316, 402-404
		Future	643-646, 693-697, 721-725, 779-805
	The expert system	Professionals assume expertise (parents' knowledge marginalised/ undervalued by themselves or professionals)	Preadmission
Admission			95-98, 109-110, 252-254, 287-289
Conditional discharge			189-200, 261-263, 518-520, 666-676
Recall			772-779
Not treated as equals, not part of team		Preadmission	600-603
		Conditional discharge	252-254, 446-449, 459-460, 607-626
Taking sides		Admission	273-283

Appendix 19: Themes and quotes from 2nd coding (Clare)

Collateral damage

1a. Process of fear-hope-loss

Preadmission

- when he was first admitted it was actually a huge relief because it had been, it's quite a confused period (2-3)
- when he first went to (*hospital unit*), I was just hugely relieved that he was somewhere where I knew he'd be safe and nobody else would be in danger for him because there was definitely a very real danger of him hurting someone and I'm, I am just still grateful that nothing happened that he'd be having to live with now. He could have ended up killing someone or killing himself because he was really in such a bad way, really very, very ill (6-10)
- at that time I was actually frightened of him. He was scaring me because he was big, he was just mad; he had that really mad look in his eyes (17-19)
- I wasn't at all surprised, I really wasn't at that time, and it really was a huge relief because as soon as they actually put a label on it, people started saying, 'oh yes, we can deal with this (24-26)
- it wasn't until he was just coming up to 17 that I actually, actually was scared of him. And that's a horrible experience to be scared of your own child. And I'd never been frightened of him until that point. But he was just beyond me. He was playing incredibly loud music all hours of the day and night as loud as he possibly could. And you could hear him talking to voices that nobody else could hear when he was in the room by himself. It was very, very scary (33-38)
- Each time I thought, oh thank goodness for that, you know, now we know what it is we can deal with it. And each time it didn't work and it got worse and it got worse. The teenage years were just a nightmare, a complete nightmare (49-51)

Admission

- my initial hope and probably expectation was that you'd be able to, you know, look at the problem, diagnose it and put it right, rather like a car, you know ... it turned out to be a little bit more complicated and take, take considerably longer than I'd expected (95-98)
- it was just total relief, and the idea, OK fine, now they know what it is, they can give him the right medicines and that's it, you know; he can live a normal life. It'll be fine (109-110)
- I somehow imagined it to be something akin to diabetes, you know he'd be simply, he'd be stabilised on this medication and he'd emerge and go to college, get a job, you know just become normal and stable (113-115)
- I thought that (*S41*) wasn't a bad thing, because I thought he's not going to be able to just [...] just take this medication and come out and then do his own thing; there's always going to be someone keeping an eye on him and saying,

you know, fine as long as you're taking your medication and you're well that's fine, we'll leave you alone, but if you don't then we're on top of you and we'll have you back. And I thought that was a good thing (120-126)

- your security just wasn't strong enough to hold him. That was horrendous, I mean that I just sat and cried when I heard that [...] I mean I couldn't say the word for, for ages. It was really, really hard, and that was a very difficult time. But I have to say the care he got there, the treatment he got was absolutely second to none. I think it was definitely a turning point (137-146)
- I suppose partly, it's the, you know there's this stigma, Broadmoor. I thought, you know, I really thought, I'm just not going to be able to ever tell anybody that (153-154)

Conditional discharge

- I was really very, very, very pleased about that (*discharge*) because he was still being very well watched over at that point. My fear all the way through when discharge started to be talked about was that he wouldn't keep his medication up. Now this was partly because Michael is so disorganised, even now. He is so disorganised and once it starts to slip then he stops seeing the purpose of it, and he has never, at that point he didn't really accept he had schizophrenia. He said, 'well they say I have, they say I need it'. So, so that was my worry that he would not take his medication, and that the whole thing would backslide, which is what ultimately happened (184-191)
- just before he was recalled [...] I saw again, that same awful look in his face that I saw when he was 17, and I was really scared again at that point, and I was hugely relieved when he was recalled, although it broke my heart, because he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful. And I, just the thought that he was losing that and it was all going to be thrown away, that [...] and it was all so unnecessary, or it seemed it to me, although now, at this point I think there was a purpose in it, in that he has learned a lot from it, and he, he does now actually accept that he is schizophrenic, which is a tremendous leap forward I think (202-212)
- he still kept coming round, but within himself he was, you know you could see he had gone back into his own world. We were irrelevant and when I drove him back to (*discharge placement*) he barely spoke to me; he was just there in the car. And if I spoke to him, he didn't, he couldn't seem to take in what I was saying, however mundane it was. I mean he was really, really ill again, really bad (224-228)
- I didn't personally feel physically intimidated by him, I mean he didn't turn on me, but I was very scared because he had that, he said he was full of anger, and he was getting into fights so I was scared for him but I was also scared because he's a big strong boy and I was very scared of what might, yeah, what he might do to other people and you know, what might happen to him, because the people he was mixing with, you know there were knives, and all sorts of nasty things. If the phone ever rang late at night, or whenever I heard a police siren, at the back of mind it was always, you know, is that something to do with Michael? (232-247)

- When I first began to suspect it, I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding. I mean I always worried about him, so I thought, well even if it does lead to him being recalled (265-269)
- it's an immense, it's very sad. Huge, huge sadness actually when you think back [...], you think back to this, this baby and toddler and innocent child and you have such high hopes for them and it's very, it is very sad (301-305)
- (*Hopes*) dashed again and again and again (312)
- there was never a question about, because I couldn't have a relationship with him when he was so ill and I knew from past experience how bad he would get. And there was this gradual shutting off from us anyway. So he wasn't in a position [...] so it was never, never, I was never torn between a relationship with him or his welfare, because I couldn't have a relationship with him if his welfare wasn't [...] and his welfare, I mean the only chance of me having a relationship with him is, if he's well. And if he gets well and I don't have a relationship with him well, you know that's, that's sad. But I'm not going to have a relationship with him anyway if he isn't well (339-348)
- they knew by his behaviour and by his results that he wasn't taking it and that was enormously reassuring to me because I thought well that's fine, you know, they can tell (370-374)
- they were much quicker than I was at that point, they were very, very good; they really were. And that was again the main worry I voiced when they were moving to (*discharge placement*) and they said did I have any concerns, that was it, that's my concern, and they said 'no, no, no, you know the outreach team, (*local community mental health team*), they will be watching him, he'll still be having these tests. But he managed to, I think he, what was it (*name of doctor*) said he did, he front-loaded or something. Anyway he, he knew the test was coming so he took the medication, but (*name of doctor*) said looking at the results now in retrospect, they should have been able to tell that he wasn't taking it. And I, when I cleared out his flat, there were over 600 tablets there, which is just [...] horrendous (378-388)
- I was scared. And I also, because he's so disorganised and chaotic, um, I was concerned about him with budgeting issues, that sort of thing and whether he'd, um, he's very haphazard, you know, but then people are different [...] So I worried about that, I worried about whether he 'd be able to cope financially. And he did get himself into a terrible, terrible mess (393-402)
- I was very worried about the people he was mixing with and influences (411)
- Before he was recalled he was in a terrible state, his personal hygiene was completely, completely gone, his clothes were in rags (417-418)
- once he was on his own, and mentally in that state, of course he wasn't eating; he wasn't washing his clothes; he wasn't washing himself. It was just gross, you could smell him coming up the road; it was just horrible; it was heart-breaking; it was distressing. And you know there's nothing you can do, I mean he's in his 20s; and then he wasn't going to pay any attention to me, I talked to him, you know, and in fact once or twice I took him off to Tesco's and bought him some clothes but it didn't last long or they disappeared (428-435)

- I was very, very grateful that he was supposed to be having this, um supervision and that they would be doing regular tests to make sure that he wasn't, um, taking drugs (504-505)
- (*Name of daughter*) was totally distraught because it had taken her a number of years to rebuild some sort of relationship with Michael and when she saw him the Christmas before he was recalled, when you consider Christmas he was in such a state, she was completely knocked sideways by it and said she just couldn't, she just didn't want to see him again. She just couldn't face it [...] She couldn't, she just couldn't cope with it (525-530, 536)
- in the end, we just all had this fatalistic, well, you know, whatever happens will happen (552-553)
- I think there is a grieving, a time of grieving where you come to realise that your child is never, never going to be, this is what I was saying about I'll never be able to say right that's it, that's Michael. He's never going to be a normal, uncomplicated, unworrying sort of person; there'll always be a slight fear over what could happen; that it could go wrong. So that, yeah there is a sort of sense of grieving, you know, what I was saying about you look back at them as children, babies, toddlers and you think, so yeah, there's the death of all the hopes that you had for them, the hopes and the expectations and you realise that's not going to happen [...] that period of backsliding that year or so before he was recalled, I think that's the point when it really did come home to me. Perhaps before then I thought well that's all right, you know, he's, he's gone through the system [...] you know, the next step is a flat on his own and perhaps a job. But I think I still had a feeling that things might just go along gradually, get better and better and better. And I think when I saw him backsliding, I knew, so I think, yeah, there was a lot of coming to terms with it then and accepting that [...] it is a bit like a bereavement (643-662)
- I can't do anything else, I'm doing what I can and, you know, just [...] part of the way I do cope with things actually is to think well what's the worst that can happen? The worst that can happen is that he will get into a fight, he will end up killing someone or being killed, um, you know, if that happens then we just cope with it. I think I gave up any idea of trying to make it right because I knew I couldn't, and I just kept every now and then ringing up (*local community mental health team*) and saying 'have you seen Michael? He is really in a bad way, he's not taking his medication' (678-684)
- I think that, that was a worry when he was being discharged, that was one of my worries, one that he would stop taking his medication and the other thing was whether he would go out drinking (699-700)

Recall

- just before he was recalled [...] I saw again, that same awful look in his face that I saw when he was 17, and I was really scared again at that point, and I was hugely relieved when he was recalled, although it broke my heart, because he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful. And I, just the thought that he was losing that and it was all going to be thrown away, that [...] and it was all so unnecessary, or it seemed it to me, although now, at this point I think there

was a purpose in it, in that he has learned a lot from it, and he, he does now actually accept that he is schizophrenic, which is a tremendous leap forward I think (202-212)

- I said 'thank goodness for that, thank goodness; I really think [...] I'm heartbroken that it's come to this, I'd have given anything for it not to have come to this, but it has, you know and I'm really pleased (572-574)
- the fact that he takes his medication and he doesn't drink, and I'm just assuming that, that even he realises drugs are completely, completely out of it, I think he's more ready to accept that he can't take drugs than that he can't drink. As far as I'm concerned, if I knew, there was no question of him drinking and I knew there was no question of his not taking his medication, then I wouldn't worry about him. I know he'd still be disorganised, I know he'd, he'd live in a degree of chaos, he wouldn't do the washing up after his meal, and he would probably get into a mess with his money now and again, but I think, you know, he could manage alright (718-725)

1b. Identity

Preadmission

- I actually, actually was scared of him. And that's a horrible experience to be scared of your own child. And I'd never been frightened of him until that point. But he was just beyond me (34-35)
- And it wasn't until he'd gone, I began to think, crikey, you know is this how everybody lives, is this, is this normal? (67-68)
- it did have a huge impact because so much time was taken up with trying to deal with his problems and just the normality of life wasn't there. He was always; he was very, very disruptive and so there just wasn't the normal, quiet, run of the mill, you know trundling along of family life (80-83)
- just a mother [...] I had the feeling that I was being thought of as, you know, neurotic, barmy mother, and perhaps it was because (*ex-husband*) and I weren't happy, I mean we hadn't been happy for many years, that somehow I was, you know, disturbed by it. I had the feeling I was the one, they always said I was the one with the problems (600-605)
- (*name of ex-husband*) would say, not only to Michael, to all of them, but he'd say to Michael 'oh take no notice of your mother, you know, she's just fussing'. And quite possibly he said that to, you know, half of the professionals, which is why I was considered this fussy over-reactive neurotic mother (749-752)

Admission

- your security just wasn't strong enough to hold him. That was horrendous, I mean that I just sat and cried when I heard that (*he was going to Broadmoor*) [...] I mean I couldn't say the word for, for ages. It was really, really hard, and that was a very difficult time (137-144)
- I suppose partly, it's the, you know there's this stigma, Broadmoor. I thought, you know, I really thought, I'm just not going to be able to ever tell anybody that. And I don't think that I spelt it out to everybody ever (153-156)

Conditional discharge

- the attitude from (*local community mental health team*), the outreach team there, was, you know, this really isn't your business, Michael is an adult and we are his support workers, and yes you're his mother and obviously you're concerned but it really isn't your business, you know, we know what we're doing and go away (609-612)
- (*Name of doctor*) came over with someone and said, you know, it's really valuable to us to know, it helps us help Michael to know your views on things. And I didn't get that at all from the (*local community mental health team*) lot, it was very much, you know, they were tolerating me and I was a bit of a nuisance, but really not seen as a resource, I was really much more of a 'oh, it's that, it's Michael's mother again', you know, 'you deal with her this time', I can just hear them saying it (618-624)
- if they'd just taken me more seriously, listen to what I was saying (672-673)

Recall

- (*Name of doctor*) came over with someone and said, you know, it's really valuable to us to know, it helps us help Michael to know your views on things (618-619)

Future

- even now I'm aware that I'm never ever going to be able to say 'oh well Michael's fine now, that's it, don't need to worry about Michael any more in the way that I can with the others (314-316)
- she said, 'well, he will be, we'll always worry about him, we'll always have to be involved. And it's tough on them actually, it's tough on the whole family (325-326)

1c. Trauma

Preadmission

- at that time I was actually frightened of him. He was scaring me because he was big, he was just mad; he had that really mad look in his eyes (17-19)
- But it wasn't until he was just coming up to 17 that I actually, actually was scared of him. And that's a horrible experience to be scared of your own child. And I'd never been frightened of him until that point. But he was just beyond me. He was playing incredibly loud music all hours of the day and night as loud as he possibly could. And you could hear him talking to voices that nobody else could hear when he was in the room by himself. It was very, very scary (33-38)
- The teenage years were just a nightmare, a complete nightmare (51)
- it was a nightmare for years and years and years. And it wasn't actually until he'd gone, when he was 17 that I realised, what an extraordinary effect, what we'd been living with (63-64)
- (*Name of daughter*) was very scared for a long time, which I didn't realise. She hadn't told me. But she told me years later that she used to barricade her bedroom door when she was in there because she was scared of Michael and she does have a phobia of knives even now. Because Michael used to play

around with knives menacingly. She was just terrified and I didn't realise for years (74-78)

- But for years you see, I was at odds, I think this probably didn't help, for years I was at odds with (*ex-husband*) I, I knew there was a problem with Michael and I wanted to take it seriously (731-732)
- We had a party one night, a Christmas party, we used to have one every year, and some friends of ours parked their car outside and Michael had gone outside and was running all over the cars and had dented the roofs of these cars. And he, he smashed every phone box between (*location*) and (*location*) (738-742)

Admission

- your security just wasn't strong enough to hold him. That was horrendous, I mean that I just sat and cried when I heard that (*he was going to Broadmoor*), I mean I couldn't say the word for, for ages (137-142)
- it's the, you know there's this stigma, Broadmoor. I thought, you know, I really thought, I'm just not going to be able to ever tell anybody that, and I don't think that I spelt it out to everybody ever (153-156)

Conditional discharge

- just before he was recalled [...] I saw again, that same awful look in his face that I saw when he was 17, and I was really scared again at that point (202-204)
- I was very scared because he had that, he said he was full of anger, and he was getting into fights so I was scared for him but I was also scared because he's a big strong boy and I was very scared of what he might do to other people, and you know, what might happen to him (234-240)
- if the phone ever rang late at night, or whenever I heard a police siren, at the back of mind it was always, you know, is that something to do with Michael? (246-247)
- (*Name of daughter*) was totally distraught because it had taken her a number of years to rebuild some sort of relationship with Michael and when she saw him the Christmas before he was recalled, when you consider Christmas he was in such a state, she was completely knocked sideways by it and said she just couldn't, she just didn't want to see him again. She just couldn't face it [...] She couldn't, she just couldn't cope with it (525-536)
- (*Name of daughter*) just cut herself off completely from him (544)

1d. Specialist services require specialist help

Admission

- your security just wasn't strong enough to hold him. That was horrendous, I mean that I just sat and cried when I heard that (*he was going to Broadmoor*), I mean I couldn't say the word for, for ages (137-142)
- it's the, you know there's this stigma, Broadmoor. I thought, you know, I really thought, I'm just not going to be able to ever tell anybody that, and I don't think that I spelt it out to everybody ever (153-156)

An impenetrable system

2a. Shut door

Preadmission

- he was all over the place; he was arrested; he was sent to one place; he was sent to another place and it seemed every time he got somewhere he was fine for a little while and then it was 'no, this isn't the right place for him, we can't contain him (3-5)
- he was just 17 when he was first actually taken over to a place, I'm not sure where it was now, somewhere in (*location*), for a residential assessment which I'd been asking for, for ages. Because he kept going to see people for an hour or so and, you know, he could hold it together for that, and um, they kept telling me that really it was my problem as much as his and so on (12-16)
- it really was a huge relief because as soon as they actually put a label on it, people started saying, 'oh yes, we can deal with this', whereas until that point everybody said 'well he's not really our, our bag, you know, we deal with this, not with, you know, we don't quite know what, what this is (24-27)
- maybe he should go and have a course of therapy and go to see a psychologist, and go to see a psychiatrist, and go and see this, and they sent (*ex-husband*) and me to family therapy, and, you know, I couldn't see any end to it at that point (30-33)
- he'd go along to see someone, to see a doctor, or whoever, and they'd sit and, and he'd say all the right things, and he came across as being perfectly rational, sensible (40-42)
- I'd been struggling since he was at primary school, there was obviously, you know, problems since he was at primary school, and each time we got a diagnosis of 'oh, he's dyslexic; oh, he's dyspraxic'. Each time I thought, oh thank goodness for that, you know, now we know what it is we can deal with it. And each time it didn't work and it got worse and it got worse. The teenage years were just a nightmare, a complete nightmare. And then the police started getting involved. And it was really once the police were involved and he got on the wrong side of the law that, and the judge said 'right, you know, you've got to do something', and that was when, that was when he started getting the help he needed. Not until he got on the wrong side of the law. Which was very sad really (47-55)
- nobody, nobody took what I was saying seriously (57)
- if they'd taken him much more seriously when he was 17, if they'd taken the problems much more seriously when he was 15, 16,17 (588-589)
- they said, no, you know, we just can't cope with him, we can't cope with this behaviour, it's not normal. And he went to (*name of special school*). And even there after a while they said, no we can't cope with this, this is, you know, and they have disturbed and difficult children there. But they didn't take him seriously nobody would take it seriously until he got into trouble with the Police. And then it went to court and the judge said, something's got to be done (592-598)

Admission

- it really was a huge relief because as soon as they actually put a label on it, people started saying, 'oh yes, we can deal with this', whereas until that point everybody said 'well he's not really our, our bag, you know, we deal with this, not with, you know, we don't quite know what, what this is (24-27)

Conditional discharge

- come along to the meetings, Michael wants you there, but, you know [...] but when it came to listening to what I was saying, just really not interested (448-449)
- I felt he was completely let down by the people who were supposed to be looking after him, and I wasn't getting anywhere, telling them (459-460)
- I spent six months at least [...] telling the people who were supposed to be supervising him that he wasn't; that 'he's not taking his medication, I know he's not, I just know it'. And they; 'well, we can't do anything, you know, until we have the proof'. I said 'but, you know, I know he's not taking it, I know he's not well' (196-200)
- that was like going back to when he was 17 and I was saying to all the doctors 'he's not well, I know he's not well, I don't know what it is, I'm not a doctor, I don't know but he's not well, he's not normal; people don't act like this (462-464)
- The chap from (*local community mental health team*), he said, 'well, unless we actually have proof, we can't, you know, we can't recall him on your say so, on you saying that. I said, 'but I know he's taking it; he's, he's told the others he's taking it, he's told my children he's taking it' [...] It was so difficult, it was so frustrating. We were all very, very worried (518-522)
- There was nothing I could do. I was trying to tell people and so really, I think, in the end, we just all had this fatalistic, well, you know, whatever happens will happen (551-553)
- the attitude from (*local community mental health team*), the outreach team there, was, you know, this really isn't your business, Michael is an adult and we are his support workers, and yes you're his mother and obviously you're concerned but it really isn't your business, you know, we know what we're doing and go away. [*interviewer* So you were?] P1: Sidelined (609-614)
- I'd told them but they weren't taking any notice (635-637)
- it would have helped enormously if I'd been taken seriously, if people had said to me, you know, right, we're listening to your worries and we will, you know, we will keep a closer watch on him and we will assess it for ourselves, but taking on board what you are saying. But you see, they didn't, I mean they'd, they didn't see him for weeks on end because they'd go round and knock on the door and he wouldn't answer so they'd go away again, and I don't know whether that was all this 'well you know it's his right not to see us if he doesn't want to', but I'm [...] so that's the one thing, if they'd just taken me more seriously, listen to what I was saying, and not necessarily accept it without looking into it themselves, but listened and taken some notice and acted on it (666-676)

- I gave up any idea of trying to make it right because I knew I couldn't, and I just kept every now and then ringing up (*local community mental health team*) and saying 'have you seen Michael? He is really in a bad way, he's not taking his medication' (682-684)

Recall

- why does it have to get so bad before anybody'll do anything. Why did he have to get, he was as bad as he was at 17 before anybody would do anything and then it's a much, much longer trek back [...] It's just not cost effective is it? I mean how much better for him, and for the nation's finances, and for us. I mean they know there's a problem with Michael, and if that could only just be caught (578-584)

2b. Engulfed

Admission

- it turned out to be a little bit more complicated and take, take considerably longer than I'd expected (96-98)

Conditional discharge

- the attitude from (*local community mental health team*), the outreach team there, was, you know, this really isn't your business, Michael is an adult and we are his support workers, and yes you're his mother and obviously you're concerned but it really isn't your business, you know, we know what we're doing and go away. [*interviewer* So you were?] P1: Sidelined (609-614)
- not seen as a resource, I was really much more of a 'oh, it's that, it's Michael's mother again', you know, 'you deal with her this time', I can just hear them saying it (623-624)

Recall

- Michael has learned a lot from that, not least he's learned that he has to toe the line otherwise other people have the power to recall him, and it's the work of a moment to be recalled, and it's a couple of years at best to work your way through the system and get out again (763-766)
- I think it's a shame that he's had to spend so long back in *medium secure unit* (772)

2c. Open door

Admission

- my friends, without exception were tremendously sympathetic and supportive, very, very good. [*Interviewer*: So what helped you get through that period?] P1: Oh I think it was the support of friends, without doubt, yeah (168-171)

Conditional discharge

- Well I certainly talked to friends yes, and they were all supportive and sympathetic but of course there was nothing they could do (298-299)

Recall

- (*Name of Doctor*) came over with someone and said, you know, it's really valuable to us to know, it helps us help Michael to know your views on things (618-619)

Responsibility

3a. Parental (doing what I can etc)

Preadmission

- I'd been struggling since he was at primary school, there was obviously, you know, problems since he was at primary school, and each time we got a diagnosis of 'oh, he's dyslexic; oh, he's dyspraxic'. Each time I thought, oh thank goodness for that, you know, now we know what it is we can deal with it (47-50)
- so much time was taken up with trying to deal with his problems (80-81)
- I felt much more in control then I think, even though I wasn't. I felt, you know, I can do this, I can make things happen and once I've made things happened and once they give him the right medication, that's it, that's fine, and then I'll just, you know, I'll sort him out [...] get his life in order (688-691)

Conditional discharge

- he'd got this flat and we had, I'd helped him get it all set up, we'd got furniture for him, and you know, kitted it all out with kitchen stuff, patterns, the whole works, and it was beautiful, beautiful (206-208)
- when I first began to suspect it. I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding. I mean I always worried about him, so I thought, well even if it does lead to him being recalled (265-269)
- Well it was different in that when he was 17, I was of course, you know, he was still at home so he was still being fed and he was, I was doing all his laundry and he was still washing and all that sort of thing, so, but once he was on his own, and mentally in that state, of course he wasn't eating; he wasn't washing his clothes; he wasn't washing himself. It was just gross, you could smell him coming up the road; it was just horrible. Oh it was heart-breaking; it was distressing. And you know there's nothing you can do, I mean he's in his 20s; and then he wasn't going to pay any attention to me, I talked to him, you know, and in fact once or twice I took him off to Tesco's and bought him some clothes but it didn't last long or they disappeared. When I cleared out his flat it was unbelievable, it was knee deep in clothes and rubbish and bottles all just tangled up together; old bits of food with fungus on; just right throughout the

flat all over the floor. It took probably the best part of a week, you know to sort stuff out, what was just rubbish to be thrown straight out, and I think it took me another week doing three loads of washing a day, to go through all his clothes and wash them and pack them all up (426-442)

- I suppose it was just thinking well I can't do anything else, I'm doing what I can and, you know, just [...] part of the way I do cope with things actually is to think well what's the worst that can happen? The worst that can happen is that he will get into a fight, he will end up killing someone or being killed, you know, if that happens then we just cope with it. I think I gave up any idea of trying to make it right because I knew I couldn't, and I just kept every now and then ringing up (*local community mental health team*) and saying 'have you seen Michael? He is really in a bad way, he's not taking his medication' (678-684)

Recall

- that was one benefit of him being recalled; he handed over his bankcard to me and gradually over the next year or so I eliminated his overdraft, and I just give him a certain amount of cash every week (402-404)

Future

- And even now I'm aware that I'm never ever going to be able to say 'oh well Michael's fine now, that's it, don't need to worry about Michael any more in the way that I can with the others. You know I can say (*Name of daughter*)'s fine now, she's qualified, you know, she's OK, barring unforeseen accidents or whatever, but by and large, I know she's OK. And it affects them as well, because (*daughter*) said to me once, she said, 'well you're not going to live forever, and then he's going to be our responsibility', and I've said to her, 'well he's not, you mustn't, you know, he's not your responsibility. But she said, 'well, he will be, we'll always worry about him, we'll always have to be involved. And it's tough on them actually, it's tough on the whole family (314-326)

Legal superiority

- And it was really once the police were involved and he got on the wrong side of the law that, and the judge said 'right, you know, you've got to do something' (52-54)
- they didn't take him seriously nobody would take it seriously until he got into trouble with the Police. And then it went to court and the judge said, something's got to be done (596-598)

3b. Handed to professionals

Admission

- my initial hope and probably expectation was that you'd be able to, you know, look at the problem, diagnose it and put it right, rather like a car, you know (95-96)

- I think it was just total relief, and the idea, OK fine, now they know what it is, they can give him the right medicines and that's it, you know; he can live a normal life. It'll be fine (109-110)
- I thought that (S37/41) wasn't a bad thing, because I thought he's not going to be able to just [...] just take this medication and come out and then do his own thing; there's always going to be someone keeping an eye on him and saying, you know, fine as long as you're taking your medication and you're well that's fine, we'll leave you alone, but if you don't then we're on top of you and we'll have you back. And I thought that was a good thing (120-126)
- I was really very, very, very pleased about that because he was still being very well watched over at that point (184-185)
- But when it came down to it we have to do what's best for your child and... if the best thing for him was to be there, then that's what I had to support. I've always said to him, you know, that these are medical decisions, and you know, I can't, I'm not medical and if they think you've got this or you need that, then you do (287-291)

Conditional discharge

- He was taking his medication. Now there was a time when they said he wasn't taking it and although they didn't have the physical proof, they didn't have the tablets, they didn't know what he'd done with them, with the, they knew, they knew by his behaviour and by his results that he wasn't taking it and that was enormously reassuring to me because I thought well that's fine, you know, they can tell. At that point I actually wouldn't have been sure that he wasn't taking it. So they were much quicker than I was at that point, they were very, very good (368-378)
- I was very, very grateful that he was supposed to be having this supervision and that they would be doing regular tests to make sure that he wasn't taking drugs (504-505)

Recall

- that was one benefit of him being recalled; he handed over his bankcard to me and gradually over the next year or so I eliminated his overdraft, and I just give him a certain amount of cash every week (402-404)
- (*Name of Doctor*) felt quite strongly that he still needed to be in residential; you know, he's the expert and I'm not, and that's, that's a medical decision in a way and I would, I would concede that because I don't have the expertise to make those judgements. So I wouldn't want to fight for what I wanted over something that (*name of Doctor*) felt was better because I trust his judgement on that (774-778)

3c. Uncertainty as to who has responsibility

Conditional discharge

- I've always gone to his review meetings and been involved because he's always been willing for me to be, and um, but they would never, never, you

know, just like when he was a teenager, I'm not the professional, so I don't know (252-254)

- I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose (266-267)
- they said did I have any concerns, that was it, that's my concern, (*non-compliance with medication*) and they said 'no, no, no, you know the outreach team, (*local community mental health team*), they will be watching him, he'll still be having these tests (380-382)
- Yeah, come along to the meetings, Michael wants you there, but, you know [...] but when it came to listening to what I was saying, just really not interested (448-449)
- The chap from (*local community mental health team*), he said, 'well, unless we actually have proof, we can't, you know, we can't recall him on your say so, on you saying that. I said, 'but I know he's taking it; he's, he's told the others he's taking it, he's told my children he's taking it'. It was so difficult, it was so frustrating. We were all very, very worried (518-522)
- The police got involved. And at that point (*Name of social worker*), at (*local community mental health team*), phoned me up and said 'Well, you know, I'm sorry but we're going to have to' as if I'd been saying, you know, 'you mustn't recall him' He said 'I'm sorry but we going to have to' you know, 'we've held on as long as we can' (567-570)
- When Michael went back into (*unit*), (*name of Doctor*). came over with someone and said, you know, it's really valuable to us to know, it helps us help Michael to know your views on things. And I didn't get that at all from the (*local community mental health team*) lot, it was very much, you know, they were tolerating me and I was a bit of a nuisance (616-621)
- They [*discharge placement*] said we know he's not taking his medication, we've been told by the other residents that he boasts about how he takes his medication just before a test but other than that he's not taking it, so [...] they'd told them, I'd told them but they weren't taking any notice (633-637)
- Well I think it would have helped enormously if I'd been taken seriously, if people had said to me, you know, right, we're listening to your worries and we will, you know, we will keep a closer watch on him and we will assess it for ourselves, but taking on board what you are saying. But you see, they didn't [...] so that's the one thing, if they'd just taken me more seriously, listen to what I was saying, and not necessarily accept it without looking into it themselves, but I think they, they should have thought, well, you know, listened and taken some notice and acted on it (666-676)

3d. Blaming and feeling blamed

Preadmission

- nobody, nobody took what I was saying seriously (57)
- if they'd taken him much more seriously when he was 17, if they'd taken the problems much more seriously when he was 15, 16,17 But they didn't take him seriously nobody would take it seriously until he got into trouble with the Police (588-589, 596-597)

- I had the feeling that I was being thought of as, you know, neurotic, barmy mother, and perhaps it was because (*ex-husband*) and I weren't happy, I mean we hadn't been happy for many years, that somehow I was, you know, disturbed by it. I had the feeling I was the one, they always said I was the one with the problems (602-605)
- (*Name of ex-husband*) would say, not only to Michael, to all of them, but he'd say to Michael 'oh take no notice of your mother, you know, she's just fussing'. And quite possibly he said that to, you know, half of the professionals, which is why I was considered this fussy over-reactive neurotic mother (749-752)

Admission

- he was transferred to Broadmoor because, because your security just wasn't strong enough to hold him. That was horrendous, I mean that I just sat and cried when I heard that (137-140)
- I've got a brother and sister who are, neither of them have children and they, they are quite critical of me. I think, I think you know they just think the whole thing was mismanaged and that if they'd had children, this wouldn't have happened to them. So I can't say that I got a lot of sympathy from them (164-167)

•

Conditional discharge

- just the thought that he was losing that [*flat*] and it was all going to be thrown away and it was all so unnecessary, or it seemed it to me (208-210)
- somebody said to me 'and if you thought he was not taking his medication would you say or would you keep it to yourself?' And I said 'No, I'd say'. I would, and I **did** say, and I said and I said and I said and nobody would listen (261-263)
- (*Name of Doctor*) said looking at the results now in retrospect, they should have been able to tell that he wasn't taking it (384-385)
- I was very, very disappointed with the supervision (451)
- I felt he was completely let down by the people who were supposed to be looking after him, and I wasn't getting anywhere, telling them (459-460)
- And at that point (*Name of social worker*), at (*local community mental health team*), phoned me up and said 'Well, you know, I'm sorry but we're going to have to' as if I'd been saying, you know, 'you mustn't recall him'(568-569)
- Well I think it would have helped enormously if I'd been taken seriously, if people had said to me, you know, right, we're listening to your worries and we will, you know, we will keep a closer watch on him and we will assess it for ourselves, but taking on board what you are saying. But you see, they didn't [...] so that's the one thing, if they'd just taken me more seriously, listen to what I was saying, and not necessarily accept it without looking into it themselves, but I think they, they should have thought, well, you know, listened and taken some notice and acted on it (666-676)

Recall

- I have said to Michael 'well you know I'm sorry, I think, I think they're right, I think you do need to be here, I think this, I think that', and he's very good

actually, he doesn't hold it against me, although at the time, he's been cross with me, he thinks, you know, I'm stupid because I've been taken in by you all (*laughs*). But later on he's generally, you know, and even then, even when he's been cross he said 'well, you know, that's your opinion, you know, you're entitled' (273-277)

Positive aspects

- But I have to say the care he got there [*Broadmoor*], the treatment he got was absolutely second to none. I think it was definitely a turning point and then when he came back to you that was, you know that was really good from thereon, it was just quite a slow, just a slow climb really (145-149)
- it [*recall*] was all so unnecessary, or it seemed it to me, although now, at this point I think there was a purpose in it, in that he has learned a lot from it, and he, he does now actually accept that he is schizophrenic, which is a tremendous leap forward I think (210-212)

3e. Infantilisation vs. autonomy / progress to independence

Preadmission

- I felt much more in control then I think, even though I wasn't. I felt, you know, I can do this, I can make things happen and once I've made things happened and once they give him the right medication, that's it, that's fine, and then I'll just, you know, I'll sort him out [...] get his life in order (688-691)

Conditional discharge

- the first few danger signs I tried to rationalise, you know, and think perhaps I'm imagining it and I'm sure he's alright, and he'd come back and he'd seem to be OK. I used to talk to him about it, because he was drinking you see which was bad news, and I'd talk to him about it and he'd say, you know when he was first beginning to backslide, he would reassure me and say, 'No, no, it's alright Mum, I know, OK, yes I've been drinking a bit much and I'm not going to', and, and put my mind at rest (215-220)
- when I first began to suspect it. I didn't want to precipitate him into being recalled, you know, because he had such a lot to lose. I wanted to try and, so I talked to him, I wanted to try and get him to pull back himself. But then, you know, I couldn't, I couldn't let it go once I saw him sliding. I mean I always worried about him, so I thought, well even if it does lead to him being recalled (265-269)
- how can you say Michael is, is in a state where he can make his own decision. I mean he's not. If he's not well, he's not able to make that decision. He can make the decision not to take the medication when he's well. But once he not taking it, then he can't make that decision anymore because he's not well enough to make that decision (483-488)
- (*Name of older son*)'s attitude was you know, 'you've got to pull yourself together, you've got to stop carrying on like this, stop drinking and eat properly and of course saying that to Michael when he's in that state is

meaningless isn't it? It doesn't, he's just not able to make any sense of it, it means nothing to him (539-542)

- (*Name of older son*)'s attitude was, you know I've had enough, it's his own fault, he's bringing it on himself, he doesn't have to do this (546-547)

Recall

- And even now I'm aware that I'm never ever going to be able to say 'oh well Michael's fine now, that's it, don't need to worry about Michael any more in the way that I can with the others (314-316)
- And that was one benefit of him being recalled; he handed over his bankcard to me and gradually over the next year or so I eliminated his overdraft, and I just give him a certain amount of cash every week (402-404)

Future

- you come to realise that your child is never, never going to be, this is what I was saying about I'll never be able to say right that's it, that's Michael. He's never going to be a normal, uncomplicated, unworrying sort of person; there'll always be a slight fear over what could happen, that it could go wrong (643-646)
- I definitely had to let that go over the years; definitely ended up feeling completely out of control, which, you know, which is fair enough, I mean the thing is nobody is really in control in a situation like Michael's. Michael's not in control, except when he's really well. I mean at the moment he is really well and I think he is able to make decisions at the moment for himself but if he makes the wrong decision and if he stops taking his medication (693-697)
- If I knew, there was no question of him drinking and I knew there was no question of his not taking his medication, then I wouldn't worry about him. I know he'd still be disorganised, I know he'd, he'd live in a degree of chaos, he wouldn't do the washing up after his meal, and he would probably get into a mess with his money now and again, but I think, you know, he could manage alright (721-725)
- I would like to see him somewhere where he's got a bit more independence and freedom, but, but with, you know, those restrictions so that he's, he wouldn't have the chance to backslide. I don't know if I can even see the point of trying to get him to the point where what's the point of putting him in a position where he can backslide? If you've got that vulnerability, if, if there's that problem there [...]. You know, it's impossible as it's possible to make it that he can't stop taking his medication and that he isn't going to start drinking or taking drugs both of which would obviously affect him. I know you have to leave him to make some of his own decisions, you know handle his own money and eat what he likes and choose his own friends [...] but I think he should be protected (779-805)

4a. Professionals assume expertise (marginalise parents' knowledge)

Preadmission

- it really was a huge relief because as soon as they actually put a label on it, people started saying, 'oh yes, we can deal with this', whereas until that point everybody said 'well he's not really our, our bag, you know, we deal with this, not with, you know, we don't quite know what, what this is (24-27)
- he'd go along to see someone, to see a doctor, or whoever, and they'd sit and, and he'd say all the right things, and he came across as being perfectly rational, sensible (40-42)
- Nobody, nobody took what I was saying seriously. And I think that's still a theme actually (57-58)
- 'We are the experts, **we** know, you've got a problem' was their attitude (62)

Admission

- Well I think my initial hope and probably expectation was that you'd be able to, you know, look at the problem, diagnose it and put it right, rather like a car, you know [...] it turned out to be a little bit more complicated and take considerably longer than I'd expected (95-98)
- I think it was just total relief, and the idea, OK fine, now they know what it is, they can give him the right medicines and that's it, you know; he can live a normal life. It'll be fine (109-110)
- I've always gone to his review meetings and been involved because he's always been willing for me to be, and um, but they would never, never, you know, just like when he was a teenager, I'm not the professional, so I don't know (252-254)
- But when it came down to it we have to do what's best for your child and... if the best thing for him was to be there, then that's what I had to support. I've always said to him, you know, that these are medical decisions, and you know, I can't, I'm not medical (287-289)

Conditional discharge

- that was my worry, that he would not take his medication. And that the whole thing would backslide, which is what ultimately happened. And I voiced that frequently. And I was told absolutely, categorically, this could not happen. He was going to be supervised. 'We will know if he doesn't take his medication', but [...] it didn't work out. I spent six months at least from Christmas until the time he was recalled in the middle of July I spent telling the people who were supposed to be supervising him that he wasn't- that 'he's not taking his medication, I know he's not, I just know it'. And they 'well, we can't do anything, you know, until we have the proof'. I said 'but, you know, I know he's not taking it, I know he's not well' (189-200)
- it might have been one of the members of the Tribunal, or (*name of Doctor*), but somebody said to me 'and if you thought he was not taking his medication would you say or would you keep it to yourself?' And I said 'No. I'd say'. I

would, and I **did** say, and I said and I said and I said and nobody would listen (261-263)

- The chap from (*local community mental health team*), he said, 'well, unless we actually have proof, we can't, you know, we can't recall him on your say so, on you saying that. I said, 'but I Know he's taking it; he's, he's told the others he's taking it, he's told my children he's taking it' (518-520)
- Well I think it would have helped enormously if I'd been taken seriously, if people had said to me, you know, right, we're listening to your worries and we will, you know, we will keep a closer watch on him and we will assess it for ourselves, but taking on board what you are saying but you see, they didn't [...] so that's the one thing, if they'd just taken me more seriously, listen to what I was saying, and not necessarily accept it without looking into it themselves, but I think they, they should have thought, well, you know, listened and taken some notice and acted on it (666-676)

Recall

- At his last Tribunal I'd have been very happy if they'd said then. 'Yes we think that you could move to somewhere more like (*name of rehab ward in the community*)'. I mean I think that would have been good. On the other hand, (*name of Doctor*) felt quite strongly that he still needed to be in residential; and as I say that's a, you know, he's the expert and I'm not, and that's, that's a medical decision in a way and I would, I would concede that because I don't have the expertise to make those judgements. So I wouldn't want to fight for what I wanted over something that (*name of Doctor*) felt was better because I trust his judgement on that (772-779)

4b. Not treated as equals, not part of team

Preadmission

- just a mother. I had the feeling that I was being thought of as, you know, neurotic, barmy mother (600-603)

Conditional discharge

- I've always gone to his review meetings and been involved because he's always been willing for me to be, but they would never, never, you know, just like when he was a teenager, I'm not the professional, so I don't know (252-254)
- So frustrating, so frustrating, and I just, what's the point of involving me... come along to the meetings, Michael wants you there, but, you know [...] but when it came to listening to what I was saying, just really not interested (446-449)
- I felt he was completely let down by the people who were supposed to be looking after him, and I wasn't getting anywhere, telling them
- When he was 17, oh yeah, I didn't get that feeling before he was recalled to be fair, but then I got the impression [...] the attitude from the outreach team there, was, you know, this really isn't your business, Michael is an adult and we are his support workers, and yes you're his mother and obviously you're

concerned but it really isn't your business, you know, we know what we're doing and go away and [...] sidelined; whereas when Michael went back into (*name of unit*), (*name of doctor*) came over with someone and said, you know, it's really valuable to us to know, it helps us help Michael to know your views on things. And I didn't get that at all from the (*local community mental health team*) lot, it was very much, you know, they were tolerating me and I was a bit of a nuisance, but really not seen as a resource, I was really much more of a 'oh, it's that, it's Michael's mother again', you know, 'you deal with her this time', I can just hear them saying it. So I didn't feel I was in any way part of his care team (607-626)

4c. Taking sides

Admission

- I have said to Michael 'well you know I'm sorry, I think, I think they're right, I think you do need to be here, I think this, I think that', and he's very good actually, he doesn't hold it against me, although at the time, he's been cross with me, he thinks, you know, I'm stupid because I've been taken in by you all (*laughs*). But later on [...] even when he's been cross he said 'well, you know, that's your opinion, you know, you're entitled'. So I have always been honest with him; I never pretended to him that I'm on his side. I mean I don't see it as sides, but he has done, even though he's perceived me as being on the wrong side from time to time (273-283)

Appendix 20: Table of themes and superordinate themes for conditional discharge and recall phases

Super-ordinate theme	Sub-themes
Emotional impact	<p>Hope and Reappraisal</p> <p>Fear and Loss</p> <p>Identity</p>
Responsibility	<p>Parents assume responsibility</p> <p>Autonomy vs. Infantilisation; Progress towards independence</p> <p>Uncertainty as to who is responsible</p> <p>Blaming and feeling blamed</p>
An impenetrable system	<p>Shut door</p> <p>Engulfed</p> <p>Open door</p>
The expert system	<p>Professionals' assumed expertise</p> <p>Not treated as equals</p>

Appendix 21: Working in partnership with psychiatrists and carers: Leaflet produced by Royal College of Psychiatrists and Princess Royal Trust for Carers, July 2010.

Working together to make a real difference



Forensic Psychiatric Services

working in partnership with psychiatrists and carers

Introduction

This leaflet is written for:

- carers who provide help and support, without pay, to a relative, partner or friend, who is being assessed or treated by forensic psychiatric services;
- psychiatrists and other members of forensic psychiatric teams who provide care and treatment for people within these services.

It suggests ways of improving communication that allow mutual respect and a working partnership to develop from the first contact with forensic psychiatric services.

For the carer

About forensic psychiatric services

Forensic psychiatric services specialise in the assessment and treatment of people with mental disorders undergoing legal or court proceedings, or who have offended.

However, people with mental disorders, who have never been involved with the criminal justice system, might also be treated in forensic psychiatric services, if they cannot be safely managed elsewhere. Treatable mental disorders include mental illness, personality disorders and learning disabilities.

The NHS provides forensic psychiatric services in healthcare and penal settings, including secure psychiatric hospitals, the courts, prisons and young offenders' institutions. Private forensic healthcare mainly provides long-stay services.

Forensic psychiatric units have different levels of security ranging from low or medium to high secure hospitals. Most patients are detained under mental health legislation, which differs in each jurisdiction of the United Kingdom and Ireland.

Psychiatric services for offenders or those accused of offending

People with mental disorders do not necessarily have to stay in the legal or judicial system. They can be transferred to the healthcare system, at the time of arrest, during court proceedings or during prison sentence.

Referral to psychiatric services can be made by a GP, other doctors, mental health professionals, police, legal professionals, courts and prison staff.

A psychiatrist and/or members of a mental health team will usually make an assessment and recommendations. They may use mental health legislation as part of the process.

Lawyers and others can commission a psychiatric report, which is paid for by the person or organisation requesting it. Psychiatric reports can only be prepared with the consent of the person concerned who must be aware that it could be given to others, including the court. Psychiatric reports usually contain an opinion and recommendations, which can affect the outcome of the legal or court processes and future psychiatric care.

Forensic psychiatric services are more likely to become involved if:

- mental health or legal issues are complex
- the offence was serious and warrants a custodial sentence
- the person might need admission to a secure psychiatric hospital
- expertise is required in the care of mentally disordered offenders

Information about the options and mental health legislation can be obtained from voluntary sector organisations (see Further Help).

Carers issues

At any stage, carers can alert the police, the courts, lawyers and health professionals to concerns about someone's mental health, care and treatment. This is important when the person is vulnerable, affected by a mental disorder, presents a risk to themselves or others, or where there are concerns about the administration of medication. Carers may wish to keep in touch with healthcare and legal professionals and give their contact details.

Carers of people involved with legal or court proceedings share similar concerns with other carers, but can have additional ones:

- they or other family members may have been victims of the offender
- the nature or severity of the offence may have upset the carer
- carers can be stigmatised by the offence and have to move home
- the carer may be excluded from the legal process

- the person may not wish the carer to be involved with their healthcare
- forensic services are often regional and can be far away from the carer's home

As a carer, you may feel:

- ashamed or guilty about the offence or the challenging behaviour
- confused about the medical and legal systems
- worried about the long-term outcome for the person
- worried about financial matters and how you will get help
- worried about the effect on you and the rest of the family
- worried about the circumstances in the hospital or prison

Tips for Carers

In partnership with your doctor and members of the forensic service team

Forming a positive relationship with all the staff and doctors involved in the care of a patient is important if the condition is long-term. Good communication between the psychiatrist, members of the forensic service team, the patient and the carer are important, but take time and effort.

The specialists you are likely to come across are: psychiatrists, psychologists, psychotherapists, psychiatric nurses, social workers and occupational therapists.

Questions to ask the doctor

- What is the diagnosis?
- Can you explain it in terms that I can understand?
- Do you have any written material on this disorder? If not, who does?
- Are there any treatments?
- Where can I get information about medication and the possible side-effects?
- How long will it take for the medication to work?
- Will there be opportunities for the patient to exercise, have education and work?

- Can they have therapy to reduce the risk of re-offending?
- Who will look after the patient's physical health?
- Are there any plans for assessment by other professionals or services?
- How long will it be before they can leave secure facilities?
- Are they still involved in the criminal justice system?
- Will they need to go back to court?
- Will they remain in hospital or could they be transferred back to prison?
- Will they have to stay in this hospital or could they be moved to a hospital closer to home?
- How do I arrange to visit?
- Can I attend reviews of clinical care?
- How can I find out about the offence?
- Are there any organisations or community services that can help me?
- Which health service worker is my main contact for guidance and advice?
- How often should I come and see you? Can we have family or support therapy?
- This person has children – how do I arrange for them to visit?

Remember to arrange your next appointment before you leave. Regular well prepared visits to the doctor or other members of the forensic psychiatric services team will help get the best care.

Advice to help you to prepare for your visits

Find out about visiting arrangements and book in advance. You may have to be registered and show photo-identification on arrival. There are restrictions on the items you can bring into secure areas, (e.g. a mobile phone). Allow plenty of time for the security procedures, as you may be searched.

During your visit:

If you do not understand something, ask questions. Do not be afraid to speak up. It may be helpful to take notes and check that there are no misunderstandings.

For follow-up visits

Review the information from your last visit and write down any questions or concerns you have had since then. This will help you to concentrate on the things that matter most. Your concerns may include questions about:

- changes in symptoms
- side-effects of medication
- general health of the patient
- your own health
- additional help needed

Further tips for carers when dealing with doctors and other members of the forensic service team

Doctors and healthcare professionals may be reluctant to discuss a person's diagnosis or treatment with the carer. There is a duty of confidentiality between the doctor and the patient. If the person is too ill to understand what is happening, doctors might involve the carer in discussions and decisions. (See our leaflet '[Carers and confidentiality in mental health](#)').

If the doctor is unwilling to involve you as the carer, you can

- ask the person if you can stay with them at some or for part of their interview
- talk with other carers as they may have some helpful suggestions
- talk to other members of the forensic service team
- contact carers' organisations in the voluntary sector or the social worker
- ask if there is a carers' support group for the forensic service

Don't forget to take care of yourself and make time for you. It is important that you talk about your worries and don't struggle alone. Try to keep in touch with friends. If you live in England, you may be entitled to a carer's assessment to identify your needs. This can be arranged through your doctor or a member of the mental health team. They should also be able to refer you to a local carers' support organisation.

For the professional

As a professional working with people in forensic psychiatric services, we hope that the following is a helpful guide to good practice.

When making an assessment, do you?

- See the person with the mental disorder and the carer separately, as well as together
- Collect collateral information

Do you allow yourself enough time to?

- Obtain and read the background information
- Take a comprehensive history
- Leave time for questions and discussion
- Explain how you arrived at the diagnosis
- Talk about the prognosis

In the management of the mental illness or disability, do you?

- Discuss possible treatments
- Talk about the possible side-effects of medication
- Spend time asking about the carer's health – physical and emotional
- Discuss how to meet the needs of both carer and the patient

Points to remember

- Everyone needs some respite
- Make it clear that you will be happy to talk to other members of the family
- Refer everyone that you see to a relevant mental health or carers' organisation
- Make it clear that someone will always be available

- Give an out-of-hours telephone number
- Make sure that there is a named professional person whom the family can contact at any time
- When you write your letter to the GP or other professionals, consider sending a copy to the patient and the carer
- Try to talk to other professionals on the telephone, as well as writing
- Make sure that the patient and carer have adequate information about the care and treatment

Further help

MIND

Mindinfo: 0845 766 0163; Legal advice service: 0845 225 9393.
Publishes a guide to mental health and the courts.

Rethink

National Advice Service: 020 8840 3188 or 0845 456 0455
Publishes information and advice on offenders with mental illness.

The Institute of Mental Health Act Practitioners

Provides useful guidance and information on the Mental Health Acts.

The Law Society

General Enquiries tel: 020 7242 1222
Publishes information on finding a legal representative.

The Princess Royal Trust for Carers

Email: support@carers.org
Provides information, support and advice to carers.

This leaflet was produced as part of the Partners in Care campaign, a joint initiative between the Royal College of Psychiatrists and The Princess Royal Trust for Carers.

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