A Critical Realist informed Thematic Analysis: Families' experience of the process of adjustment when a family member is in a forensic mental health hospital

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ABSTRACT

The experience of families who have a member in a forensic mental health hospital (FMHH) is a neglected area of research. It is understood that these families are a vulnerable population and face additional challenges e.g. violent behaviours, criminal justice system contact, to that of "carers" who care for a person with a mental health difficulty.

Families' experience of the process of adjustment when they have a member in a FMHH is a novel area of research, which this qualitative study explored. Eleven family members with a relative in a FMHH were interviewed. A Critical Realist informed Thematic Analysis was used to analyse the interviews. Two global themes emerged; "negotiating systems" and "family processes".

'Adjustment theories', 'systems theory' and 'family recovery' were used as conceptual frameworks, which have been applied to "carers" who care for a person with a mental health difficulty, to understand the findings.

Families are traumatised. The unexpected transitions of a member developing a mental health difficulty, violent behaviours and subsequent admission to a FMHH, result in a fragmented family. Families adjust to such change and form strategies to remain connected and cohesive, sometimes unhelpfully.

Families are challenged by coming into contact with dominating, powerful and intrusive systems whilst supporting their family member in to appropriate mental health services and admission to a FMHH. Families feel disempowered and disregarded, resulting in a lack of trust of the FMHH.

Families are resourceful in using their personal resilience and seeking external support to adjust to these challenges. However, when families seek support from services for themselves it is unavailable, inaccessible and/or inappropriate.

Throughout the Service Users' journey, families need to be; recognised, valued and supported. The study presents direct implications for research, policy and practice.

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List of Abbreviations

BPS British Psychological Society

CI Chief Investigator
DoH Department of Health

FMHH Forensic Mental Health Hospital

FND Family Network Day
FT Family Therapy
GP General Practitioner
GT Grounded Theory

HRA Health Regulations Authority

LC Local Collaborator
MH Mental Health

NHS National Health Service
RCPsych Royal College of Psychiatry
REC Research Ethics Committee

SU Service User
TA Thematic Analysis
UK United Kingdom

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1.0 INTRODUCTION

1.1 Overview

The present study explores how families adjust when a member is in a forensic mental health hospital (FMHH), a new area of research. A critique of concepts including, "carer", "patient" and "psychiatric disorder" are discussed. The context of "caring" in the United Kingdom (UK), the challenges families face when a relative has a mental health (MH) difficulty, and the additional challenges when that family member is in a FMHH are presented. Benefits of family contact for the service user (SU) whilst they are in a FMHH are then reported. The mismatch between FMHH policy, guidelines, provision, and research concerning families' involvement in SU care and families' support, is then addressed. Three conceptual frameworks that address change and adjustment when supporting a family member with a MH difficulty are presented and critiqued; 'adjustment models', 'systems theory', 'family recovery'. A literature review summarises the published research regarding families' experiences of having a member in a FMHH. A critique of the literature is presented and provides the rationale for the present study's research questions.

1.2 Terminology

Three major constructs used in this thesis are acknowledged and critiqued here.

1.2.1 "Carers" Or Family?

"An "informal carer" is generally defined as someone who looks after another person – a relative, neighbour or friend, but predominantly a relative – who has an impairment, mental health problem, or (chronic or life-limiting) illness" (Beresford, 2008, p.5).

The emergence of 'informal carers' arose in the mid-1970s, in the context of a hostile economic climate and political shift to the right, meaning capitalism and individual responsibility were valued (Beresford, 2008). Subsequently, the process of de-institutionalisation occurred, increasing numbers of people in the community needing care. Women within families often became "informal"

carers", which adversely affected their autonomy, health, social relationships, income levels and social security (Finch & Groves, 1983). As a result, "Carers" Rights, and thus the term "carers", is used in political contexts to draw attention to the further support required for "carers" and the "cared for".

Many claim the term should be abandoned as it fails those it should help (Molyneux, Butchard, Simpson & Murray, 2011; Pilgrim, 1999). For example, most "carers" prefer to describe themselves within their relational role e.g. wife (Cleary, Freeman & Walter, 2006) as do those "being cared for" (Henderson, 2001). This lack of identification with the term "carer" has repercussions for the utilisation of "carer" services (O'Connor, 2007). Denying previous relational roles has a negative impact on individuals' 'sense of self' (Harding & Higginson, 2001), damaging for the relationship between the "carer" and those "being cared for" (Henderson 2001). It is also a culturally-bound term (e.g. Gunaratnam, 1997) and cannot be defined under one umbrella term. It is used inconsistently and inappropriately within research. Those that advocate for its abandonment, argue that it is a socio-political construct which denies the emotional and relational aspects which motivate "caring" (Netto, 1998) and rebrands "what was a normal human experience into an unnecessarily complex phenomenon" (Molyneaux et al., 2011, p.422).

Family relationships whereby a member has a MH difficulty are more complex than other "caring" relationships (Henderson, 2001). The term "carer" emphasises a dyadic relationship, where the "cared for" impacts the "carer", negating other family members experience. Furthermore, the author believes that one cannot arbitrarily segregate the experiences of "carer" from the "SU", understanding they influence each other.

Similarly, in relation to "carers" in a FMHH context, some "carers" reject this label. Others accept it because services have identified them as "carers", or have embraced the term as it signifies change in the relationship with their relative (Ridley et al., 2014).

The present study uses the terminology "family", "family member" or relational descriptions e.g. mother, rather than "carer". The focus is on the family relationships rather than the "caregiving" role. The term "family" encompasses families, friends, and other supporters. The term "carer" is used when research

refers to "carer", but quotation marks are used to indicate the term's incongruity.

The author is aware that use of the term "family" within MH literature has negative associations, such that they are perceived either as burdened "carers", as causing, or sustaining the mental illness in a family member, or contributing to relapse (Bland & Foster, 2012).

1.2.2 "Patient" Or Service User?

Terms used by those who commission or provide services, and those in receipt of those services, are controversial. Literature generally labels people as "patients" when residing in FMHH. Some research has found that those using MH services prefer to be labelled as "patients" or "clients", as opposed to "service user" or "survivor" (e.g. Simmons, Hawley, Gale, & Sivakumaran, 2010; McGuire-Snieckus, McCabe & Priebe, 2003), others advocate for the latter (National Survivor User Network). This study addresses people who use MH services as Service Users (SU). However, the author is aware of the associated criticism and it is not used to harm, i.e. restrict people's identities, or imply passivity (National Survivor User Network, 2017).

1.2.3 Psychiatric "Disorder" Or Distress?

Mental Health services are structured around psychiatric diagnostic frameworks e.g. International Classification of Diseases version 10 (ICD-10: World Health Organisation, 1992) and therefore SU receive psychiatric "disorder" label(s) without choice. Many contest the use of psychiatric diagnoses as not useful or valid (e.g. Timmi, 2014). Others recognise their importance e.g. a useful form of communication (e.g. Craddock & Mynors-Wallis, 2014). The author does not agree with the psychiatric framework or use of these constructs and understands them as harmful (National Survivor User Network, 2017). When diagnostic terms are used within this study, inverted commas are used to highlight the controversy.

1.3 Context

This section discusses the importance of "carers" in the UK and families' experience of having a member with a MH difficulty. It sets out the context of FMHH, and the circumstances in which SU are admitted. Policy and guidelines

concerning family involvement and family support in FMHH are outlined, and current provision and evaluation of these.

1.3.1 "Caring" For People With Mental Health Needs

There is high prevalence rate of MH "disorders" in the general population (McManus, Bebbington, Jenkins & Brugha, 2016), although "severe and enduring" MH difficulties such as "psychosis" and "antisocial personality disorder" (ASPD) are estimated at one per cent (Bebbington et al., 2016) and four to eleven per cent respectively (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006; Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2000; McManus, Meltzer, Brugha, Bebbington & Jenkins, 2009).

There are thought to be 6.5 million informal "carers" in the UK, with 13% caring for people with MH needs (Carers UK, 2015). Others report higher figures e.g. 24% (Arksey, 2003). These figures are an under-representation, due to issues related to the "carer" label (see section 1.2.1) and not surveying secondary "carers" i.e. siblings.

"Carers" are considered a vast economic resource in the UK (Guberman et al., 2003; Anderson, Mikulic, Vermeylen, Lyly-Yrjanainen. & Zigante, 2009; Department of Health (DoH), 2010), and their contribution has been increasingly acknowledged (Pickard, 2008; Glendinning et al., 2009; Buckner & Yeandle, 2011), with support of "carers" rights groups (e.g. Carers Tust). UK legislation has recognised "carers" since The Carers Act 1995 (DoH, 1995) and more recently in The Care Act 2014.

Glendinning and Arksey (2008) identified four approaches to "carer" policy: "carer as resource", "carers as co-workers", "carers as co-clients", and "the superseded carer". They concluded that current policies are primarily based on the "carer as resource" model, where the "carers" are treated as a resource, only supporting their well-being to maintain care-giving. They suggest that until the underpinning conceptual model shifts, it is likely that "carers" will continue to experience a myriad of negative outcomes.

1.3.1.1 Experience of caring for a person with mental health needsMost people with MH needs do not need caring support. However, where need

exists, it considerably impacts on "carers" lives. Literature examining the impact of a family member's MH difficulty on the family has been couched in terms of "carer burden". The impact of providing care for a member with a MH difficulty is multidimensional (Schene, van Wijingaarden & Koeter, 1998; Szmuker et al., 1996). The role of "Carer" for someone with a MH difficulty includes: being oncall, providing emotional support, ensuring medication adherence, navigating the MH system with the SU, supporting inpatient admission, monitoring and managing symptom fluctuations (Stefani, Seidmann, Pano, Acrich & Bail Pupko, 2003; Schulze & Rossler, 2005; Jeon & Madjar, 1998).

"Caring" for someone with a MH difficulty may be more challenging than "caring" for someone with a physical illness, as the journey of the person with MH difficulty may follow a more turbulent and unpredictable course, making caring a more disruptive process, while those with physical illness are more likely to be motivated to recover and comply with treatment (Karp & Tanarugsachock, 2000). "Carers" experiences vary according to factors such as duration, contact time, relationship and type of support required, as well as accessibility to, and acceptability of, formal services. The "carer's" contexts of gender, age, ethnicity and sexuality, also affect caring experiences (Ray, Bernard & Phillips, 2009; Ridley, Hunter & Rosengard, 2010; Larkin, 2012).

"Caring" for a person with MH difficulties is associated with "subjective burdens" e.g. grief, anger, guilt and shame (Thompson & Doll, 1982; Fadden, Bebbington & Kuipers, 1987; Maurin & Boyd, 1990; Loukissa, 1995; Marsh & Johnson, 1997; Baronet, 1999; Foldemo, Gullberg, Ek, & Bogren, 2005; Kilyon & Smith, 2009). "Objective burdens" such as physical illness, financial problems, and taking time off work to provide care, are experienced (Awad & Voruganti, 2008; Repper, 2008). The quality of relationship with the distressed person changes e.g. progressive dependence (Stefani et al., 2003), as do relationships within and outside the family, e.g. being marginalised and lacking social support (Berry, Barrowclough & Wearden, 2007; Castle, McGrath, & Kulkarni, 2000). Such caregivers suffer increased rates of MH difficulties, (Kuipers, Onwumere & Bebbington, 2010), suicidal behaviours and fatigue compared to the general population (Stansfeld et al., 2014). These ongoing stresses are conceptualised as "secondary trauma" (Wyder & Bland, 2014).

Few studies have examined positive adjustment outcomes for these "carers"; those published report mixed findings (Chen & Greenberg, 2004; Winefield, 2000). "Carers" perceiving themselves as coping, reported benefitting from increased self-confidence, inner strength, maturity, and life experience (Bauer, Koepke, Sterzinger, & Spiessl, 2012).

In summary, families who support a member with a MH difficulty face many challneges, that change over time. Legislation positions "carers" as resources, without adequate support.

1.3.2 Forensic Hospitals, Service Users And Families

1.3.2.1 Forensic services

FMHH are directly commissioned by the National Health Service (NHS) England, a specialist tier four service, as part of an integrated care pathway and include high, medium and low secure inpatient and outpatient services. Most SUs enter FMHH from CJS, general MH services, or transfer from other FMHH (NHS Confederation, 2012).

There are three high secure hospitals in England. No comprehensive list of medium or low secure units in England and Wales exists, although, Davies, Mallows, Easton, Morrey and Wood (2014) identified 65 medium secure units (private, NHS). Approximately 7719 inpatient beds are commissioned (795-high, 3192-medium, 3732-low: NHS England, 2013). There is little research that evaluates FMHH, although evidence suggests that SU discharged from secure services have lower offending outcomes than comparative groups (Fazel, Fimińska, Cocks & Coid, 2016).

1.3.2.2 Service users

Service Users admitted to FMHH have complex needs including MH difficulties, have been in contact with the criminal justice system (CJS), present serious risk of harm to themselves or others, and have the potential to abscond. All SUs are detained under the Mental Health Act 1983, 2007. Of those detained under part III (patients concerned in criminal proceedings or under sentence) of the Act, 78% of SU are men (Ministry of Justice, 2010). Such SUs are diagnosed with one or more "severe and enduring" MH "disorders" such as "psychosis" or

"personality disorders", with approximately 50-60% having "diagnoses" of "schizophrenia" (Jansman-Hart, Seto, Crocker, Nicholls, & Côté, 2011).

Compared to the general population, people with a "schizophrenia diagnosis" are more likely to commit a violent crime (Angermeyer, 2000; Brennan, Mednick, & Hodgins, 2000; Eronen, Angermeyer, & Schulze, 1998; Hodgins, Mednick, Brennan, Schulsinger, & Engberg, 1996; Tiihonen, Isohanni, Rasanen, Koiranen, & Moring, 1997), although their contribution to overall criminality in society is small (Swanson, 1994). Within the prison population, prevalence rates of "ASPD" vary from 10% (Gunn, Maden, & Swinton, 1991) to 78% (Singleton, Meltzer, Gatward, Coid, & Deasey, 1998). Due to SU complex needs, the construct of "dual" or "mixed diagnosis", and issues with the psychiatric diagnostic system generally, rates of diagnoses are unknown within FMHH.

Violence to others is the prime reason for FMHH admissions (Chiswick & Cope, 1995), with victims likely to be a "carer" or spouse (Estroff, Swanson, Lachicotte, Swartz, & Bolduc, 1998; Steadman et al., 1998; Nordström & Kullgren, 2003). Aggression from relatives is positively related to lasting trauma symptoms in "carers" (Loughland et al., 2009; Hanzawa et al., 2013). Other challenges faced by families with a member in a FMHH, e.g. the media, contact with the CJS, are detailed within the literature review (section 1.5).

1.3.2.3 Families

It is not known how many "informal carers" of SU in FMHH there are. However, it is understood from staff surveys that approximately 70% of families stay in contact with their relative when admitted to a FMHH (Ridley et al., 2014; Absalom, McGovern, Gooding & Tarrier, 2010; Canning, O'Reilly, Wressel, Cannon & Walker, 2009). Levels of contact are thought to be underestimated, as staff do not regard families as "carers" (Ridely et al., 2014). Parents, rather than spouses or siblings, are more likely to be "carers" in this context (Ridley et al., 2010).

Copeland (2007) conceptualised families who have members with a MH difficulty and are violent as 'vulnerable'. "Carers" of people with "schizophrenia" and forensic history, compared to "carers" of people with "schizophrenia" and

non-offending history, are more likely to experience more severe difficulties and rate violence and annoyance with services as more burdensome (MacInnes & Watson, 2002). Furthermore, the needs of relatives caring for SU in medium secure units (in England) are more complex than relatives of SU in community settings (in Spain: Absalom-Hornby, Gooding & Tarrier, 2011).

1.3.2.4 Benefits of family support to the service user

Research analysing narratives of SU recovery highlights the importance of interdependence and positive interaction with people following development of a MH difficulty (Roe & Davidson, 2005). For some SU, the family fulfils this role. Not all SU have "family" or benefit from these relationships, indeed, family members may impede recovery (EnglandKennedy & Horton, 2011; Tew et al., 2012).

Service Users within a FMHH have reduced opportunity to maintain social support (e.g. Barksy & West, 2007). "Connectedness", an important process in SU recovery in a FMHH, includes maintaining relationships with family members (Clarke, Lumbard, Sambrook & Kerr, 2016; Shepherd, Doyle, Sanders & Shawl, 2016). These relationships are considered important materially and provide a context in which the SU can view change in themselves (Shepherd et al., 2016).

Moreover, "carer burden" and ability to cope has a recognised impact on SU recovery in a FMHH (Chein & Wong, 2007; Kuipers et al., 2010). "Carers" stressors, e.g. travel and financial problems may lead to reduced contact, and support, of the SU (Evans, 1996; McCann & McKeown, 1995).

Reduced social support for the SU contributes to their difficulties in adjusting to a FMHH environment (McCann, McKeown & Porter, 1996) and their anxieties about discharge (Main & Gudjonsson, 2005). Furthermore, SU-family contact is a significant factor associated with a shorter stay in FMHH and a positive discharge (Castro, Cockerton & Birke, 2002).

Within offender rehabilitation literature there is support for the development of interventions that promote inclusion and involvement of families e.g. The Good

Lives Model (Ward & Maruna, 2007), which identifies 'relatedness' as a primary goal for offender populations. Family involvement is also understood to be a key risk management strategy in risk assessment tools, such as the HCR-20 v3 (Douglas, Hart, Webster & Belfrage, 2013).

1.3.3 Policy Relating To Family Support And Involvement In Service User Care In Forensic Services, Provision And Research.

1.3.3.1 Policy

Governmental MH strategies (e.g. DoH, 2011), legislation (e.g. Care Act 2014) and clinical guidelines (e.g. NICE, 2009ab, 2014) are only partly applicable to FMHH. Family involvement in SU care within guidelines for best practice for FMHH is not a new concept in policy (e.g. Health Offender Partnerships, 2007). Recent standards for low and medium FMHH (Royal College of Psychiatrists (RCPsych), 2017a) describe seven standards regarding "family and friends"; three relate to families' involvement in SU care, e.g. "carers" are invited to be involved in SU treatment, if appropriate, and four to family support e.g. signposting to a Carer's Assessment. No similar standards for high secure FMHH exist.

More recently NHS service specifications for FMHH (NHS England, 2018), require FMHH to have a "carer engagement and involvement strategy", that enables families to be involved in SUs care, defines how families' needs will be supported by the service, and prioritises the maintenance of family relationships.

The standards and specifications set out by the RCPscyh (2017a) and NHS (2018) provide guidelines but lack detail regarding implementation. It could be suggested that clinical guidelines from the National Institute of Clinical Excellence (NICE), could provide more specificity and direction, however, the most comprehensive i.e. NICE guidelines for "Psychosis" (NICE, 2014) lack detail.

NICE guidelines are based on evidence from non-offending populations, they do not suggest adaptations to support these SUs and their families. The challenges of using NICE guidelines within a FMHH are compounded by the

complexity of the SU needs and challenges FMHH must consider when involving families e.g. victim issues, complex and disrupted care pathways via prison and MH services, and availability of appropriate local support services.

In summary, FMHH lack a clear strategy to implement policy, with the specificity or sensitivity required to address these families' complex needs.

1.3.3.2 Provision and evaluation of family support and family therapy
FMHH have not systematically evaluated "carers" support (Ridley et al., 2014),
or family therapy services (Davies et al., 2014), perhaps because of the
complex nature of "carers" support needs and family work in FMHH, constraints
on clinicians' time, or the staff skill set.

1.3.3.2.1 Family support

The RCPsych (2017b) annual review of medium secure settings reports that services fully met 53% of standards relating to "family and friends", ranging from 0-100% compliance, scoring poorly across both domains of families' involvement in SU care and family support.

Prior to these standards (RCPsych, 2016, 2017a), several surveys in the UK attempted to identify provision, type and access to, families' support in FMHH. Two-thirds to three quarters of FMHH provided at least one type of "carers" support (Cormac, Lindon, Jones, Gedeon & Ferriter, 2010; Canning et al, 2009, Ridley et al., 2014). Most often a named nurse or information leaflet was provided. Other support included; information about statutory Carer's Assessment, travel grants, SU-"carer" social events, liaison workers, accommodation and a dedicated telephone line, although such support was inconsistent across hospitals (Canning et al., 2009; Ridley et al., 2014; Cormac et al., 2010). High secure hospitals are understood to be best resourced to support "carers" in England (Canning et al. 2009) and Scotland (Ridley et al., 2014). Less than half of "carers" are thought to access FMHH support (Canning et al., 2009; Ridley et al., 2014). The authors attribute this to a lack of identification with the "carer" label.

Some FMHH offer "carers" support groups (Cormac et al. 2010; Canning et al., 2009, Ridley et al., 2014), others signpost "carers" to third sector support

groups, but it is not known whether these were attended, or carers' needs met (Ridley et al., 2014).

A "carers" support group in a high secure hospital in England was evaluated, the benefits included; reduced isolation, feeling hopeful, increased communication with staff, and involvement in SU care (McCann,1993). More recently, Ridley and colleagues (2014) found that "carers" reported additional benefits of: access to information, learning from others, personal fulfilment arising from contributing, and reduction of felt stigma (Ridley et al., 2014).

1.3.3.2.2 Family therapy

Family therapies are thought transferable to FMHH (Richards, Doyle, & Cook, 2009). Some have argued that there are likely to be distinguishable features of family intervention in this setting, in contrast to non-offending populations, because of the forensic case formulation (Sturmey & McMurran, 2011) and risk management (Nagi & Davies, 2010, 2015).

Less than half of medium secure hospitals in England and Wales offer Family Therapy (FT) with Systematic Psychotherapy as the main theoretical approach, without adequate training or supervision (Davies et al., 2014; Cormac et al., 2010). Few families are offered FT and even less receive it (Smith, Bickerdike & Forsyth, 2013). FT provision has not been researched in high secure services in England.

Richards and colleagues (2009) found no evaluative studies of family therapy within a FMHH. The author has found two pieces of research that evaluate family intervention within FMHH, a pilot psychoeducation programme, (Nagi & Davies, 2015), and a web-based CBT focused family intervention (Absalom-Hornby, Gooding, & Tarrier, 2012); the former had few participants, the latter is a family case study. Both describe benefits for families, including increased knowledge about MH. Descriptive studies suggest family intervention is a space where victims of the offence can process trauma and verbalise fears (Robinson et al., 1991), and can provide increased ability to cope with stress and communicate feelings (Ridley et al., 2014).

In summary, accessibility to, and type of family support and family therapy, varies considerably between FMHHs, with some not compliant with current guidance. No research identifies why many families are not receiving/accessing the support offered. There appears to be a discrepancy between policy specifications, what is practiced and research that evaluates this.

1.4 Conceptual Frameworks Of Family Adjustment

This section introduces the conceptual frameworks of 'adjustment', 'systems theory' (and associated family therapies) and 'family recovery' that have been applied to families with a member with a MH difficulty. These provide alternative perspectives of how the process of change and adjustment in families could be understood, in the context of FMHH. It is acknowledged that the constructs of e.g. hope, acceptance, and processes experienced, e.g. recovery, resilience, adjustment, are conceptually unclear, subjective and relative to the person's cultural and socio-political contexts.

1.4.1 Adjustment Models

Within the present study adjustment refers to the responses families made to a change in the environment that allowed them to adapt (Sharpe & Curran, 2006). Two models for conceptualising families' adjustment to these circumstances are given; "stress and coping model of adjustment" (Mackay & Pakenham, 2012) and a "resilience" framework (Zauszniewski & Bekhet, 2015), these cross-over conceptually, but have different emphases.

Adjustment literature refers to concepts such as "stress", "burden", "coping" and "resilience". Measures have been developed to quantify adjustment such as Quality of Life (QoL), mental health questionnaires, and levels of "carer burden". Outcomes are generally binary with a person being positively adjusted or maladjusted. As noted above (section 1.3.1.1) supporting a family member with a MH difficulty, is associated with high levels of "carer burden" and MH difficulties.

1.4.1.1 Stress and Coping model of adjustment

The "Stress and Coping Model of Adjustment to Caring for an Adult with Mental Illness" (Mackay & Pakenham, 2012) is based upon Lazarus and Folkman's

(1984) stress and coping theory, which suggests that stress emerges when the relationship between person and environment is appraised by the person as exceeding his/her resources and threatening well-being. Adjustment to caregiving and the SU illness is determined by three cognitive, behavioural and interpersonal processes: cognitive appraisal, coping strategies and coping resources, and contextual factors e.g. time spent caring, influence adjustment to caregiving.

Coping resources are relatively stable, personal characteristics e.g. 'optimism', or environments e.g. 'social support', which facilitate positive adaptation to stressors (Billings & Moos, 1982). Cognitive appraisals are processes that reflect a person's interpretation of an event (Lazarus & Folkman, 1984). Events are appraised in terms of threat and challenge (primary appraisal) and controllability (secondary appraisal).

Coping strategies are "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman 1984, p.141). Coping strategies have been categorised as problem-focussed and emotionally-focussed, which is either avoidant or emotional. Meaning-focussed coping has been suggested as an additional strategy, whereby people create, reinstate or reinforce meaning to a distressing event (Park & Folkman, 1997).

Better caregiver adjustment is related to higher levels of optimism and social support and, better quality of SU-"carer" relationship, lower threat and higher challenge appraisals, and less reliance on avoidance-coping (Mackay & Packenham, 2012). The same research highlighted daily caregiving, "objective burden" e.g. job loss, and SU symptom unpredictability, show poorer "carer" adjustment.

The authors, however, do not account for all the known factors that have been found to influence families' adjustment e.g. "carer"-professional contact (Schene et al.,1998). More recently, research shows those "caring" for a person with MH difficulties for less than 20hours per week appear to have lower levels of distress (Crowe & Brinkley, 2015). Higher levels of burden have been associated with emotional-focused, rather than problem-focussed coping

(Nafiah, 2015), whereas self-care had a modifying effect on levels of "burden" (Han, Diwan, Chang, Comfort & Forward, 2017).

1.4.1.2 Resilience

It is debated whether "resilience" is a characteristic/personal quality, a process or an outcome (Ahern, Ark, & Byers, 2008); various definitions exist.

Nevertheless, theorists agree that resilience is in place when successful adaptation to adversity (i.e. high-risk situation or threat) occurs (Luthar, Cicchetti, & Becker, 2000; Masten, 2001; Schilling, 2008).

Zauszniewski & Bekhet (2015) applied resilience theory to families with a member with a MH difficulty. Within the literature they found seven indicators of resilience; "acceptance", "hardiness", "hope", "mastery", "self-efficacy", "a sense of coherence" and "resourcefulness", that were characteristics of families who are better at managing and overcoming adversities (Zauszneiewski & Bekhet, 2015).

1.4.1.3 Critique of adjustment research

The most significant critique of adjustment literature is the way in which adjustment is measured, as variables are used interchangeably as predictors and indicators e.g. depressive behaviour has been identified as a predictor (e.g. Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2002) and consequence of adjustment to a physical illness (e.g. Cordova, Cunningham, Carlson & Andrykowski, 2001; Griffin & Rabkin, 1998). Moreover, outcomes used to measure adjustment are simplistic and cannot account for the complexity of the lived experience.

Cultural and religious beliefs impact on how families perceive MH, support the SU and seek resources (e.g. Lien, 1993; Pacquiao, 2008; Sabogal, Maron, Otero-Sabogal, Maron, & Perez-Stable, 1987; Mzimkulu & Simbayi, 2006) and adjustment models do not account for these.

Finally, these models are individualistic, focussing on cognitive process, with the onus on the person to change these to enable adjustment. They perceive the SU-"carer" relationship as isolated from other familial relationships, with the SU impacting the "carer," rather than the relationship being mutually dynamic. They do not account for the families' strengths.

1.4.2 Recovery Approach

'Relational' and 'family recovery' is the second conceptual framework to explore change in families, which stems from a critique of the "individualistic" approach of the personal recovery literature.

1.4.2.1 Personal recovery

The recovery approach is currently the most influential paradigm shaping Western MH policy and practice (Slade et al., 2014; Braslow, 2013). It emerged from the anti-psychiatric and survivor movements in the 1960s and 1970s and became a 'vision' in the 1990s.

The language of 'recovery' emanates from two traditions (Slade, 2009). One promotes a biological view, where distress is labelled as "disorders", that are assumed chronic, incurable deviations from 'typical' brain functioning. This medical model emphasises 'clinical recovery'; symptom remission, and ability to return to a functioning baseline as measured by 'standardised' outcome measures (Braslow, 2013). Whereas psychosocial personal recovery promotes a process leading to a meaningful, satisfying, empowered and hopeful life, despite fluctuating distress (Slade et al., 2014; Anthony, 1993).

There is little consensus on the 'model' of personal recovery (for review see Andresen, Oades & Caputi, 2011). One model, CHIME (connectedness, hope, identity, meaningfulness and empowerment: Leamy, Bird, Le Boutillier, Williams, & Slade, 2011) synthesises 'personal recovery processes' reported in the literature. MH services adopting the recovery approach support these processes, by supporting the SU's personal recovery e.g. positive relationships, satisfying work, development of cultural or spiritual perspectives. This is underpinned in policy such as the Care Planning Approach (CPA: DoH, 1990).

1.4.2.2 Critique of the personal recovery approach

The recovery approach is an important alternative to coercive, deficit-based MH practices, and is well-supported. However, it is frequently challenged concept,

described as; 'conceptually fuzzy' (Roberts & Wolfson, 2004), underpinned by an individualistic world view, (Adeponle, Whitley, & Kirmayer, 2012; Price-Robertson Obradovic & Morgan, 2016) and the original ideas of recovery have been manipulated by governments and MH professionals to align themselves with the biomedical discourse (Harper & Speed, 2013; Hunt & Resnick, 2015; Rose, 2014).

The critique relevant to the present study is how 'recovery' is almost always defined at the individual level (Topor, Borg, Di Girolamo, & Davidson, 2011) the onus of recovery rests on the individual, while the social, material and political contexts of recovery are largely obscured (Adeponle et al., 2012; Harper & Speed, 2013; Duff, 2016). Despite social and structural determinants such as health care provision, family support, education attainment and/or progressive workplace arrangements, being consistently identified as among the strongest predictors of positive MH outcomes (Allen, Balfour, Bell & Marmot, 2014; Furlong, 2015).

There is further criticism from non-Western collectivistic cultures who emphasise families' interdependence in managing distress, rather than independence, promoted in Western cultures (Slade et al., 2014).

The dominant view in which adult criminality is viewed is similar to that of the recovery model; an individual phenomenon, where the person who breaks the law is accountable. Change lies with the individual rather than with social systems where criminal behaviours occur (Haney, 2005; Haney & Zimbardo, 1998).

1.4.2.3 Relational and family recovery

The assertion that SU are responsible for their recovery could suggest that families may not have a place in SU recovery. However, as suggested in section 1.3.2.4, staying connected to families can positively impact on SU recovery. Most often the families' role is defined as being supportive of SU recovery, as opposed to recovery occurring within relationships i.e. 'relational recovery' or 'family recovery' where families undergo a separate but parallel process to the SU.

It is argued by those suggesting the concept of 'relational recovery' that while interpersonal relationships are currently recognised as a component of the personal recovery process, social processes underpin all aspects of recovery i.e. hope, identity and empowerment (Price-Robertson et al., 2016). Findings from interviews with SU who had "recovered", emphasised relationships don't shape process but are the 'space' within which processes take place (Schön, Denhov & Topor, 2009).

'Family recovery' on the other hand, could be understood as a necessary consequence of the SU recovery, i.e. as the SU "recovers", the relationships and power balance within the family alters, thus the family need to adapt. A model of 'family recovery' by Wyder and Bland (2014) recognises that the process of SU recovery is relational, and recognises that family members undergo a separate recovery process.

Wyder and Bland (2014) describe 'SU recovery', 'recovery-oriented support' and 'family recovery' using the processes from personal recovery models i.e. CHIME (Leamy et al., 2011; Davidson, O'Connell, Tondora & Lawless, 2005). 'Recovery-oriented support' refers to support families offer the SU to aid their recovery e.g. families support the SU to form relationships with the wider community. They suggest 'family recovery' involves family members: using social support to feel connected and accessing support to re-gain a sense of control, maintaining hope for themselves, moving away from the primary "carer" identity by accepting and developing new meaning to their life, adjusting to their disempowerment in relation to MH services and re-positioning themselves in an advocacy role.

Modifying psychoeducational interventions developed for families who have a member diagnosed with "schizophrenia", by adapting language, content and outcomes, could be made consistent with a 'family recovery' approach (Glynn Cohen, Dixon & Niv, 2006).

1.4.3 Systems Theory And Family Therapy

'Systems theory' and schools of family therapy provide the final conceptual framework for understanding the process of change in families.

Feedback is a key principle of systems theory: "how information could loop back into a system in order to enable control in the form of adjustments to be made" (Dallos & Draper, 2015, p.28). In relation to families, systems theory contends that individuals do not live in isolation, but interact within a social and environmental context.

Families with a member in a FMHH (like any other) are a system made up of more than a group of individuals, they have relationships between members (holism) with each member influencing one another (circularity). The family system is dynamic and co-evolves with its environment (Hoffman, 1982) and is influenced by both external and internal events, thus experience fluctuates. The family develops over time through its life cycle (e.g. Carter & McGoldrick, 1980) and is required to adapt to these changes. Problems are understood to occur when the family has difficulties in adjusting to disruptions within the family life cycle. These changes include, composition (e.g. marriages), individual development (e.g. gaining employment) and unexpected (e.g. illness). Families therefore fluctuate between change and stability, and self-regulate (Robinson, 1980). When stressors arise, families re/develop structures and rules to regain stability (homeostasis). Negative feedback refers to complementary changes made by family members when a change occurs, keeping the system balanced. In contrast, positive feedback occurs when a change in the system is exaggerated by the family, disrupting the homeostatic system. The impact of feedback could be positive or negative.

These ideas rest significantly on family/individual life cycle models and normative assumptions about 'healthy family functioning'. Wider societal expectations such as gender roles and inequalities, are not considered. However, they provide a framework that can capture process of change when the family is challenged.

Families who have a member in a FMHH must adapt to the unexpected family transitions of a member developing a MH difficulty and/or violent behaviours and the subsequent admission to a FMHH. It is hypothesised that problems occur within families following these unexpected and sometimes rapid transitions, it is not known what occurs and how families adjust.

Different schools of family therapy provide alternative hypotheses about ways in which families adjust to internal/external challenges. Structural therapy theorises that, in a transition period, families must renegotiate structures, roles and rules (Minuchin, 1974). Whereas Strategic therapy theorises that families are likely to respond to disruption according to traditional patterns of interacting and problem-solving. Systemic therapists consider that families have a more fluid response to an event, and try to re-establish homeostasis within the system.

Within the prison-offending literature, Datchi, Barretti and Thompson (2016) apply systemic theory to the family and the incarceration of male prisoners; they address the family 'created' as opposed to family of origin. They suggest that incarceration represents a transition point in the family life cycle that calls for a shift in family roles and responsibilities, i.e. those on the outside must adjust to the absence of the incarcerated relative and balance the needs of family and prisoner (Braman, 2007; Christian, Mellow & Thomas, 2006).

1.4.4 Summary Of Conceptual Frameworks

The conceptual frameworks presented here are used to explore families' process of adjustment when they have a member in a FMHH.

Adjustment models focus on the impact of the SU on the "carer" and are primarily based at the individual level i.e. cognitive and behavioural responses to change and the person's use of personal characteristics and external resources.

In contrast, the ideas of relational and family recovery are focussed on the "carer-SU relationship" as interrelated and reciprocal. Relational recovery theorises that SU recovery occurs within the relationship. Family recovery incorporates this idea, and that families go through a process of change that fluctuates, but generally moves from interdependence with the SU "recovery" to independence. It acknowledges that families undergo their own recovery process, with which they may need support. It could be hypothesised that 'family recovery' process for families in a FMHH context may be different from

families with a member with a MH difficulty, due to the number and severity of challenges faced.

Here, Systems theory, goes beyond understanding the SU-"carer" relationship. It perceives the family as an inter-connected system, that adjusts to change, during transition periods, and processes i.e. role change, patterns of communicating, that may hinder or benefit the family.

1.5 Literature Review: Families Experience Of Having A Member In A Forensic Mental Health Hospital

A systematic search and review of the literature related to families' experiences when a member is in a FMHH was conducted. See Appendix A for the literature review strategy and outcome. Fifteen articles were considered relevant, see Table 1 for a description of the literature from the review.

Table 1: Description of literature from literature search

Authors	Country	Aim	Type of secure hospital/s ervice	Number of participants and demographics	Study design	Instruments used
Absalom- Hornby, Gooding, & Tarrier, (2011a).	England	Needs of relatives of a family member in a FMHH	2 Medium Secure hospitals	N=18, all relatives, 44%mothers Ethnicity demographics not reported. All SU diagnosis of "schizophrenia"	Cross- sectional design using structured questionnaire s Telephone interview. Quantitative- percentages and elaborated with qualitative data.	Adapted- Family Questionnaire (Quinn, Barrowclough & Tarrier, 2003), 48 items administered via interview. Adapted- Relatives Cardinal Needs Schedule (Barrowclough, Marshall, Lockwood, Quinn & Selwood, 1998), comprised of 14 sections gaining info on relative's support, ongoing relationships, hardships and emotions in relationships to family member with a diagnosis of "schizophrenia".
Ferriter, & Huband, (2003).	UK	Explore the opinion of parents of the cause of the "disorder", emotional burden and	Not detailed, but all patients in a FMHH in UK selected at	N=22, all parents, 64%mothers, All n white. All SU diagnosis of "schizophrenia"	Qualitative- structured interviews.	Experience of child's "illness" was determined using 3 methods: Endorse theories of causation (Kaplan & Sadock, 1989), Degree of Burden Scale (Thompson & Doll, 1982),

		perception of helpfulness of others.	random.			Focused Life Story Interview (Tagg, 1985).
Livingston, Crocker, Nicholls, & Seto, (2016).	Canada	Explore how SU', relatives and professionals perceive FMH tribunals	Not detailed, 50% patients in FMHH and 50% community discharge.	N= 13 relatives (26 SU's, 16 professionals). SU diagnosis not specified.	Qualitative- Semi- structured interviews- phone/person Thematic Analysis (Braun & Clarke, 2006)	
MacInnes, (1999).	PhD not accessible but likely to be England – see MacInnes &Watson (2002)	Unpublished PhD thesis- Perceptions of relatives and informal caregivers of "schizophreni a offenders". Not accessed.			Ciarke, 2000)	
MacInnes, (2000).	Review	Review- Needs of caregivers of having a SU in a FMHH,				

		interventions, social and professional contact and illness representatio ns.				
MacInnes, Beer, Reynolds, & Kinane, (2013).	England	To gain an understandin g of "Carer's" satisfaction with services in FMHH	Medium Secure hospital	N=63, 75% parents, 64% mothers. Ethnicity demographics not reported. SU diagnosis not specified.	Structured interview- analysed both quantitative and qualitative based upon a priori themes.	Interview schedule focused on the following thematic areas: Experience of prior MH services, experience of relative/friend moving to MSU, information received from services, psychological impact of caring, ward environment, involvement in care, discharge planning.
MacInnes, & Watson, (2002).	England	Examining level of burden experienced by caregivers of individuals with a diagnosis of "schizophreni a", comparison between	SU from regional secure unit or acute inpatient.	N= 79 forensic caregivers, 57% mothers, 8% friend, 59% Black N= 28 non-forensic caregivers, 46% mothers, 4% friend, 43% Black. All SU diagnosis of	Survey with in-depth semistructured interviews. Content analysis (Viney, 1983)	Interview schedule focused on the following thematic areas of burden: Specific difficulties faced by caregivers, frequency of burdens faced, most worrying burdens, coping with burdens, cause of the burdens.

McCann, McKeown, & Porter, (1996).	England	caregivers of forensic and non-forensic patients. Identify needs of relatives in relation to knowledge and understandin g of "schizophreni a", establish levels of stress on relatives and its impact.	High secure	"schizophrenia" N= 14 relatives (and 3 friends) of 11 SU's. Ethnicity demographics not reported. All SU diagnosis of "schizophrenia"	Qualitative with semistructured interview	Relative Assessment Interview, Schizophrenia in a Secure Environment (McKeown & McCann, 1995), a semi- structured interview based on Relative Assessment Interview (Tarrier et al., 1998) and Schizophrenia Nursing Assessment Protocol (Brooker & Baguley, 1990). The focus is on relatives perceptions and beliefs of contact with SU. Knowledge and Schizophrenia
						Interview (Barrowclough et al., 1987). Semi structured interview assessing functional knowledge of relatives.
Nordström,	Sweden	Exploring	SU recent	N= 14 parents of	Qualitative	Interview schedule focused on
Kullgren, &		parents	admission	11 SU, 64%	with semi-	the following thematic areas:
Dahlgren,		emotional	to FMHH	mothers.	structured	Experience of violence,
(2006).		experience of			interview.	experience of psychiatric care,
		having an		Ethnicity		reactions within the family and
		adult son with		demographics not	Based on	significant others, possible

		a diagnosis of "schizophreni a" and committed a crime.		reported. All SU diagnosis of "schizophrenia"	principles of grounded theory (Glasser, 1978; Struss & Corbin, 1990)	measures of prevention.
Pearson, & Tsang, (2004).	Hong Kong	Testing use of Tsnag et al., (2002) stress and burden model of relatives experience of having a family member in a FMHH.	FMHH- security unknown.	N= 23 relatives, 39% mothers. Ethnicity demographics not reported. SU diagnosis not specified.	Qualitative – semi-structured.	Relative Assessment Interview (Barrowclough & Tarrier, 1992) and adapted and converted in to Chinese. Provides information on problems and needs of caregivers of SU with a diagnosis of "schizophrenia".
Ridley, McKeown, Machin, Rosengard, Little, Briggs, Deypurkaysth a, (2014).	Scotland	Exploring experience of being a "forensic carer" and their experience of support.	High, medium/lo w FMHH and community forensic mental health services.	Survey N= 66, 54% parents, higher % of female respondents. Ethnicity: All but one, were white/Scottish Interviews N= 19, 63% parents	Qualitative with questionnaire survey and interviews. Analysis: "standard qualitative data analysis methods,	Questionnaire was formed around: Details about themselves (e.g. age, gender, ethnicity, etc.), and about the person they cared for, their experiences of forensic mental health services, the nature of carer support including independent carers advocacy that they were both aware of and/or had used, their

				Ethnicity: All white/Scottish.	starting with coding and identifying key themes and patterns in the data (Coffey & Atkinson, 1996; Bazeley, 2013)" pg.11.	experience of the person they cared for being transferred into or between forensic mental health services, the key challenges they had faced in this role, and for suggestions about how support to forensic carers could improve. Interview topics included: experience of being a forensic carer; about moves from prison or general psychiatric services to forensic mental health services and changes in level of secure services; about their experience of forensic mental health services' support to carers including carer support groups; and for their suggestions about improving carer support.
Rowaert, Vandevelde, Lemmens, & Audenaert, (2017).	Belgium	Experience of family members who have a family	25% SU in community , 21% in prison, the rest in	N= 24 relatives, 48% mothers. Ethnicity demographics not	Qualitative- semi- structured interviews.	Interview topics included: experiences of family members regarding the psychiatric history of their relative, the legal proceedings and the internment

		member serving an 'internment measure' i.e. FMHH.	inpatient FMHH	reported.	Thematic Analysis (Braun & Clarke, 2006)	measure they were confronted with, impact of the psychiatric problems and the internment measure on family members, coping strategies, strengths of family members and future perspectives.
Rowaert, Vandevelde, Lemmens, Vanderplasshen, Vander Beken, Vander Laenen, & Audenaert, (2016).	Review	Review- literature search- role and experience of family members of SU in a FMHH. 6 identified studies.				
Tsang, Pearson, & Yuen, (2002).	Review	Development of stress and burden model of relative's experience of having a family member in a FMHH.				

Tsang, Pearson, & Yuen, (2006).	Hong Kong	A re- production of Pearson &			
		Tsang			
		(2004).			

The review identified five themes, including; "carer" role, identified needs and "burdens", perception of SU care, experience of contact with the FMHH (information, visiting, support) and forms of coping.

1.5.1 Experience Of The Changing Role

"Carers" follow the complex journey the SU makes through services, reporting the longevity of their needs, mirroring the length of stay of their relative and changing over time (Ridley et al., 2014).

"Carers" described their role as providing emotional and practical support e.g. visiting, bringing gifts, being a 'named person', advocacy, maintaining contact with other family members, and being a point of contact for services (Ridley et al., 2014). Some "carers" felt their role was suspended or "inadequate", when their relative was admitted. Others felt "powerless" and "intimidated" by the FMHH and become "institutionalised" (Ridley et al., 2014).

"Carers" are affected by the SU transitions between services e.g. the level of support offered and accepted and face new challenges, learning new ward/hospital processes and communicating with different teams (Ridley et al., 2014). Further pressure is felt when their family member moves from FMHH to community services (Ridley et al., 2014); many unaware of community-based rehabilitation possibilities (Ferriter & Huband, 2003). "Carers" experienced ambivalence when considering having their relative to live with them at discharge; balancing affection, duty and fear (Ferriter & Huband, 2003). Some families believe their safety is not considered by professionals when making discharge decisions (Pearson & Tsang 2004; Tsang, Pearson & Yuen, 2006).

Personal growth has been described by some, but this is not elaborated upon (Ridley et al., 2014).

1.5.2 "Carer Burden" And Identified Needs

There is little published literature about the experience of these families; what exists focusses on "burdens" (Ridley et al., 2014). The majority find this role as profoundly stressful, although some view their role as implicit and not "burdensome" (Ridley et al., 2014).

A model of these families' stress and "burden" suggests that such families are more likely to feel more burdened than those caring for a person who has not offended (Tsang et al., 2002). The model theorises four dimensions of burden (symptom specific, social, emotional and financial) with core sources of stress as the criminal offence and management of the SU MH, with secondary sources being associated with the offence; dealing with the media and police, court proceedings and FMHH admission (Tsang et al., 2002).

1.5.2.1 Stigma and social isolation

Stigma has been identified as a stress for these families (McCann et al.,1996) and a major challenge faced (Ridley et al., 2014). "Carers" in Belgium described the double-stigma of having a relative with MH needs who has additionally committed a criminal offence (Rowaert, Vandevelde, Lemmens & Audenaert, 2017).

Consequently, family members tell few people (including other relatives), about events related to the SU (Pearson & Tsang, 2004; Tsang et al., 2006; McCann et al., 1996), some have lost friends, feel socially isolated, (Ridley et al., 2014) and withdraw socially (Pearson & Tsang 2004; Tsang et al., 2006).

Some "caregivers" become resistant to stigma (Rowaert et al., 2017); others feel their identity becomes defined in terms of their relationship with a stigmatised relative (Ridley et al., 2014).

In contrast, caregivers of those who care for a person with a "diagnosis of schizophrenia" with a forensic history were less likely to recount stigma-related "burdens", than caregivers of a person with the same "diagnosis" but without a forensic history (MacInnes & Watson, 2002). Furthermore, relatives of a person in a medium secure unit described 'lower' needs in relation to their relationships, in contrast to "carers" of someone with MH needs in the community (Absalom-Hornby et al., 2011). The author of the present study hypothesises that "carers" within the community, physically separated from the SU due to being in an FMHH, can more easily differentiate between their caring role and community life. In contrast, "carers" caring for a person in the community are more directly involved with the SU, have less time for other relationships and are confronted with stigma by association.

1.5.2.2 Managing symptoms and violence

"Carers" manage the SU symptoms and their violent and antisocial behaviours (Ferriter & Huband, 2003; Absalom-Hornby et al., 2011; MacInnes & Watson, 2002); more so than those who care for family members with equivalent "diagnoses" who have not offended (MacInnes & Watson, 2002). Relatives feel trapped, not knowing how to respond to such behaviours (Ferriter & Huband, 2003, Absalom-Hornby et al., 2011). Parents are also protective in defending their child and desensitised to their violent behaviour (Ferriter & Huband, 2003).

1.5.2.3 Emotional and physical impact

Experiences of relief, un/informed and shock are described by families when a member is admitted to a FMHH (MacInnes, Beer, Reynolds & Kinane, 2013; Ridley et al., 2014). Generally, families report negative emotions related to this experience e.g. anxiety, anger, grief, confusion and hopelessness (Ridley et al., 2014; McCann et al.,1996; Ferriter & Huband, 2003; MacInnes & Watson, 2002).

These families are frequently quoted in the literature expressing guilt, failure and self-blame. Some feel responsible for the MH difficulty itself and/or not noticing the SU's earlier distress (Rowaert et al., 2017; Ferriter & Huband, 2003). Self-blame persists despite reassurance from others and absence of 'other'-blame (Ferriter & Huband, 2003).

"Carers" expressed sadness and anger that a criminal offence "had to" occur before the SU received mandatory treatment, i.e. the MH system had 'failed' to prevent the offence (Rowaert et al., 2017). Relatives also worry that their family member will never be discharged (Livingston, Crocker, Nicholls & Seto, 2016).

Families' emotional experience is affected over time. Emotions of guilt, self-blame, grief, fear, and disappointment are present during the initial stages (onset of mental illness', 'receiving a diagnosis', 'violent/criminal behaviour') of the SU journey and develop positive reactions i.e. relief and hope, following referral to a FMHH (Nordström, Kullgren, & Dahlgren, 2006).

Families report reduced resistance to physical illness and an impact on their own MH, as a consequence of managing SU distress and violence (Ridley et al., 2014).

Services rarely cater for the emotional needs of the family (Ridley et al., 2014). Relatives want their own negative emotions to be addressed (Absalom-Hornby et al., 2011) and have reported that counselling would be helpful (Ridley et al., 2014).

1.5.2.4 Media

Relatives reported that media involvement is extremely stressful, (McCann et al., 1996) as is being publicly "outed" in relation to the SU's offence (Pearson & Tsang, 2004: Tsang et al., 2006).

1.5.2.5 Financial impact

'Financial burden' is a stressor for these families (Ferriter & Huband, 2003), more so than for "carers" of relatives with "schizophrenia" and non-offending histories (MacInnes & Watson, 2002), associated with difficulties in maintaining employment (Ridley et al., 2014).

1.5.2.6 Criminal justice system

"Carers" experience significant stress when confronted with the CJS (McCann et al., 1996).

"Carers" in Belgium reported frustration about their relative's case management, that legal aid counsel was costly and lacked appropriate knowledge, although it was helpful in supporting the prison–FMHH move (Rowaert et al., 2017).

Relatives feel excluded from Forensic Mental Health Tribunals in Canada as they lack information about the court process. Tribunals provoke parents' anxiety, worry and fear, then relief once the hearing finishes, (Livingston, Crocker, Nicholls & Seto, 2016). The relatives' voice becomes lost within this research, as it is amalgamated with SU and professionals' perspectives.

In summary, these families face multiple stressors which have detrimental impacts on their way of life. Despite the wealth of information focussing on

families "burdens", research is still limited. The present study seeks further information regarding "burdens", alongside an exploration of how families cope with these.

1.5.3 Perception Of Service User Care

It is difficult to disentangle families' experience of support received and involvement in SU care, as support in one can benefit the other (Ridley et al., 2014).

"Carers" experience of FMHH is affected by the perceptions they have regarding the care of the SU within the FMHH, and report this as a stress (McCann et al., 1996). These families have lower levels of satisfaction with services than caregivers of persons in community settings, (MacInnes, 1999) and parents, relative to other "carers" of SU in a FMHH, have lower levels of satisfaction overall with services (MacInnes et al., 2013).

Service Users' perception of care (e.g. staffing consistency, ward environment, involvement in care and relationships with clinical teams) is considered by "carers" as variable (Ridley et al., 2014; MacInnes et al., 2013). "Carers" are critical of high doses of medication and the controlling nature of sedative drugs. Although, "carers" reported care within FMHH had improved over time, not all needs were met, particularly of SU with "autism spectrum conditions" and "learning disabilities" (Ridley et al., 2014).

1.5.4 Experience Of Contact With Secure Mental Health Services

1.5.4.1 Information and communication

"Carers" supporting a SU in a FMHH are more likely to report annoyance with services as a severe burden, in contrast to caregivers supporting a SU who has not offended (MacInnes & Watson, 2002).

Information provided by the hospital is the factor most associated with overall service satisfaction by "carers" (MacInnes et al., 2013), and services vary in their proactivity in offering and responding to information requests (Ridley et al., 2014). "Carers" wanted different types of information regarding SU care such as: outcome of SU assessments, the treatment pathway, hospital and ward, practical information, (Ridley et al., 2014; MacInnes et al., 2013). When

provided, this information is perceived to be of inconsistent quality (Ridley et al., 2014), "carers" report feeling "fobbed off" by professionals; reporting that information was withheld, incomplete or incomprehensible (Ferriter & Huband, 2003; Rowaert et al., 2017).

"Carers" want to be involved in SU care and are annoyed at being unable to participate, especially not having access to information that could directly affect the family (MacInnes & Watson, 2002). "Carers' are said by professionals to be routinely invited to CPAs in Scotland, although this does not reflect their involvement in these meetings (Ridley et al., 2014).

"Carers "report that the barriers to receiving information are: confidentiality issues, the organisation's culture and ability to visit (e.g. travel, time: Ridley et al., 2014). Families in Hong Kong were concerned that being 'visible' to FMHH could encourage untimely discharge into the community, so refrained from asking for information (Pearson & Tsang, 2004; Tsang et al., 2006).

Gaining information from FMHH regarding SU care and support for families, appears to be a significant challenge. Whilst wanting to participate in SU care, families didn't always feel included.

1.5.4.2 Visiting

Visiting family members in forensic hospitals is considered important to "carers" (Ridley et al., 2014), although it can be stressful due to SU aggression (McCann et al., 1996); "carers" can feel "dread" and "guilt" prior to visiting (Ridley et al., 2014). Distance and travel time impacts on frequency of visits. "Carers" experience is affected by aspects of the physical environment e.g. lack of privacy, security process, staff support, visiting times, and financial support (Ridely et al. 2014).

Given the challenges of visiting SU at FMHH, it would be interesting to know why families visit and how they overcome these challenges.

1.5.4.3 Help and support

"Professional support" is a significant need of relatives (although not defined: Absalom-Hornby et al., 2011). "Carers" also want information from hospitals regarding their rights and support services (Ridley et al., 2014; MacInnes et al.,

2013). Family members report "fighting for recognition" of, and support for, themselves and the SU (Rowaert et al., 2017).

"Carers" access support from a range of services including the FMHH, victim liaison, advocacy, support groups and police. Access to, and the helpfulness of this support is variable (Ridley et al., 2014; Ferriter & Huband, 2003). For example, not all carers receive information regarding a statutory "carer" assessment (<40per cent) and due to the time taken to obtain one, they are dismissed as un-helpful (Ridley et al., 2014).

Mental health professionals and nurses are regarded as less caring or indifferent towards "carers" compared to other professionals, "carers" suggest this represents a barrier to their support (Ferriter & Huband, 2003; Ridley et al., 2014). Consequently "carers", feel neglected and angry towards services (Ferriter & Huband, 2003).

Benefits of "carers" support include 'feeling understood,' being treated 'as part of the solution as opposed to the problem' (Ridley et al., 2014) and feeling valued rather than blamed (Ferriter & Huband, 2003).

Despite the "carer burdens" presented above, there is little known about families' experience of support from services, but research suggests that families want and need this. The family-FMHH relationship appears to be a factor in how support is perceived.

1.5.5 "Carers" Forms Of Coping

The final section of the literature review reflects research that identifies "carers" use of resources and strategies to cope with their challenges.

Authors have suggested that caregivers' 'coping' is associated with attributed illness representations, for example, 'constructive coping' i.e. where caregivers agree with the SU "diagnosis" and believe there is an environmental influence (except drugs/alcohol: MacInnes, 1999, 2000). Others suggest that adaptive strategies include; attributing the offence to the SU's MH, maintaining a social network and contact with the SU, or maladaptive; 'bottling-up feelings', withdrawing from others, desiring revenge against others and/or SU (McCann & McKeown, 1995; McCann et al., 1996).

Families rate their family and self-help groups as supportive (Ferriter & Huband, 2003), reporting feeling less alone, less stigmatised and better able to cope when sharing their stories (Rowaert et al., 2017) and caring responsibility (Ridley et al., 2014).

"Carers" believe positive events for the SU at the FMHH e.g. success in treatment, a good relationship with psychologist, 'strengthen' the SU and in turn themselves, to support their relative. They also maintain hope that the SU can lead a happier life in future (Rowaert et al., 2017).

Work and hobbies e.g. reading, playing music distract from the "caring role" (Rowaert et al., 2017; Ridley et al., 2014).

There is little known about what or how families use resources when they have a member in a FMHH, no study has explicitly explored this.

1.6 Critique Of Literature And Rationale Of Research Study

1.6.1 Description Of Research: Number Of Studies And Country Conducted
Of the 15 publications found in the literature search (see Table 1), three were
literature reviews and one (Tsang et al., 2006), a re-publication of an earlier
study (Pearson, & Tsang, 2004). Eleven research publications were therefore
considered within the literature review, although one of these was an
unpublished PhD thesis (MacInnes, 1999) and was not accessible. Six of the 10
studies were conducted in UK (1 Scotland, 4 England, 1 unspecified UK), two
conducted by the same author, the largest study within the UK to date is that of
Ridley et al. (2014) conducted in Scotland. The other four studies were
conducted in Hong Kong, Canada, Belgium and Sweden. The research
conducted in Canada (Livingston et al., 2016), however, merged the experience
of "carers", SU and professionals and thus "carers" experience isn't explicit
within the analysis.

Across the international literature there is a lack of research that explores families' experience of having a family member in a FMHH. Different countries have different ethical, legal and medical practices, thus the systems with which families must interact, are assumed to be different and their experience is likely

to depend on this. Although the majority of studies appear to be from the UK, its constituent countries have different legislation in place and follow different clinical health and social care guidance e.g. in England and Wales, health and social care is guided by National Institute of Clinical Excellence (NICE), whereas Scotland follows guidance from the Scottish Medicines Consortium (SMC) and the Scottish Intercollegiate Guidelines Network (SIGN). Additionally, within the UK the countries have varying service provision due to allocation of resources and demand. Therefore, it could be assumed that families have different experiences based on the differences between countries and their medical and legal systems.

The four studies conducted within England cross a time span of almost 20 years (1996-2013), during this time an evolutionary change in the provision of secure services has occurred, with a shift away from high to medium secure provision (Rutherford & Duggan, 2007). Thus, families within these studies may have had different experiences depending on the provision of FMHH's provided for at the time. Moreover, during this period, research, theory and practices within mental health services have slowly adjusted from focussing on the cause of MH difficulties to ways in which distress can be managed and supported. Moreover, theory and research related to how families are perceived in relation to causing and maintaining a family member's MH, or supporting the SU's recovery has changed during this period. Additionally, MH awareness by the public has increased during this time, due to third-sector campaigns by MIND and Re-Think within the UK, and thus the issues of stigma and discrimination experienced by "carers" could be assumed to have also changed. Furthermore, no research has been conducted in England (or Wales) since the Care Act 2014, the law which legislates for the rights of the "carer" including those who care for those with MH difficulties. This, coupled with the strengthening of the "carers" rights movement, "carers" access to support and therefore experience, could also be assumed to have changed.

Due to the limited number of studies conducted, including those in England, the long time-spans involved over which these have been conducted, and the cultural, legal, medical, and clinical psychology theory and practice changes that have occurred within this time, it is argued that further research is required

to explore families' current experience of having a family member in a FMHH, in England.

1.6.2 Critique Of Sample And Methodology

The qualitative studies used sample sizes of 13-79 relatives/ "carers", the majority of participants were parents and more often mothers. To have an enriched understanding of the "families'" experience, it would be valuable to know whether other family members' perspectives exist, other than those of mothers in regard to their experience of having a family member in a FMHH.

Although all studies were described as "qualitative" and some described as "exploratory", many used structured interview instruments to gather data e.g. Relative Assessment Interview (Tarrier et al., 1998). Three of the six conducted in the UK used interview instruments, adapted to the forensic context; the other three used semi-structured interviews, basing their topic guide on prior literature, one using a priori themes to conduct the analysis (MacInnes et al., 2013). The research available does not offer much with regard to "exploring" families' experience, but rather identifies "carers" needs using structured tools developed in a particular time and theoretical context. The current research aims to explore families' experience as opposed to defining it using cultural and historical assumptions and conceptual understanding.

The analytical approaches used across the research studies included; Content analysis (1), Thematic Analysis (2), Grounded Theory (1), unspecified qualitative analysis (2) or used an analysis approach according to the interview instrument (4). The lack of specificity of the analytical method and epistemological position, brings into question the quality of the research. The authors do not attend to methodological processes to ensure its trustworthiness (Lincoln & Guba, 1975).

The current study aims to invite other family members as well as the mother to participate in the research, and recruit enough participants to satisfy a qualitative methodological approach. This study aims to enrich the field using research questions which are designed to be exploratory, without preassumptions, unlike previous research, and to use an established qualitative

methodology to bring rigor to this research area.

1.6.3 Critique Of Focus Of Literature And Lack Of Application To Conceptual Frameworks

The focus of the studies generated from the literature review is on "carers" understanding of the cause of "schizophrenia" and "carers" needs and burdens associated with caring for a family member with a diagnosis of "schizophrenia" who is in or has been in a FMHH. Those that aim to explore "carers" experience more generally, construct their qualitative analysis around "carer burden", thus limiting the breadth of "carers" experience. The most recent literature by Rowaert et al. (2017), supported by their literature review (Rowaert et al., 2016), attempts to divert the focus from "carer burden" to strengths of families and ways in which families cope with the "burdens" and "stresses" of caring for a relative with a diagnosis of "schizophrenia" and offending behaviours. This is an important development in the field, drawing upon positive psychology ideas, as it considers families as active and able participants, that can have an impact on their experience by using their knowledge and skills to adjust to their negative experiences. However, Rowaert et al. (2017) do not develop these ideas in depth, describing behaviours in which families "cope", but do not address these ideas in relation to a conceptual psychological framework, such as 'resilience theory' or 'recovery models'. To develop this research field, exploring how families adapt to having a member in a FMHH, the resources they use and whether changes occur over time, would be beneficial to research and practice.

The research within the literature review is descriptive of "carers" experience and lacks application to prior psychological theory/models; it therefore fails to be in line with the "carer" literature more generally. Two pieces of literature within the review, however, initiate the development of conceptual frameworks to be applied to "carers" experience of caring for a family member in a FMHH. Tsang et al. (2002) developed a model of stress and "burden" of relatives' experience of having a family member in a FMHH, based on the limited available literature of "carers" experience of having a family member in a FMHH. This model clarifies the additional "burdens" on "carers" who have a family member in a FMHH experience, relative to "carers" who care for a family member who has a

MH difficulty. The authors don't attempt to base their model on previous frameworks, it lacks depth in relation to psychological processes e.g. 'cognitive strategies' that prior models such as Mackay and Pakenham (2012) address in their stress and burden model of being a "carer" of an adult person with MH difficulties.

Secondly, Nordström et al. (2006) developed a grounded theory model of parents' emotional experience of their sons becoming mentally unwell and the process of being admitted to a FMHH. Again, this model addresses "carers' emotional burdens" and the way in which they change through time associated with the 'phase' which the SU is in. This model frames the parents as passive recipients, as their emotional experience is dependent on having their child developing a MH difficulty and subsequent FMHH admission. This model fails to address the interactive effect of the relationships between the family, SU and services. Additionally, this model ignores how families perceive the ways in which they cope and what families do to adjust to these emotional experiences.

The research presents the experience of "carers" in the context of the; "carer" caring for the SU, the SU burdening the "carer", and thus the "carer" having needs, this relationship is not positioned within the context of the family. The literature does not consider the family being a caring unit or the inter-relational impact on others in the family. The impact on relationships within families as a consequence of having a member in a FMHH, is unknown. Conceptual ideas from systems theory and family therapies could aid the understanding of families' experiences and move the field forward, away from the perception that the "carer"- SU relationship is the only affected relationship.

Moreover, current research provides a static view of the burdens that families experience prior to SU admission and the immediate impact post-admission to a FMHH. There is little known about the challenges families face subsequently, whilst the SU stays within a FMHH. Additionally, benefits of having a family member in a FMHH previously not reported could be explored.

In summary, the scope of research that has been conducted around families' experiences of having a family member in a FMHH is limited, focussing on "carer burden" and a dyadic relationship between a "carer" and a SU, which is

perceived as static. The literature is mainly descriptive with little attempt to apply to psychological concepts/models. The aim of this research is to explore the families' strengths and resources, the challenges faced and whether perceived as changing. Additionally, it aims to explore whether current psychological paradigms are applicable to these families' experiences.

1.6.4 Author's Position To Research Area

As an assistant and trainee psychologist working within FMHHs, I observed that families were generally absent from clinical discussions regarding the care of the SU and even less apparent in relation to how the FMHH supported families. However, when families were discussed during clinical meetings they were spoken about in the following ways: 1) Families were spoken about as victims of the SU offences and not discussed in detail, any concerns raised were framed outside of the team's responsibility. 2) Families were discussed when a "visit" or phone contact from the family had gone "wrong", and the clinical team had to decide how staff would manage future visits, usually resulting in asking certain family members not to visit/contact. 3) Families were most often discussed in relation to the cause of the SU's distress e.g. abuse, parenting style or maintaining the distress e.g. critical of SU during visits. 4) Families were described as being a "nuisance" to hospital e.g. telephoning too often, asking too many questions or being hostile or confrontational to a staff member. During my professional work, I wondered what was the experience of these families? What was the impact on the family system? What changed as a result of this experience of having a family member in a FMHH? Who did they have to support them? Was formal/informal support available to them? Did families benefit from the SU being in a FMHH?

When I witnessed the few families that visited the FMHHs, they were distressed, confused and overwhelmed. I was curious about how they managed these difficult emotional experiences, where was the space to process this? Did different family members adapt in different ways? I was aware of the lack of opportunity families have to access emotional and practical support from the FMHH, including psychological interventions that include the family i.e. family therapy.

My own experience confirms much of the literature summarised in the literature review, in relation to how I perceive the challenges families face and needs of families when a family member is in a FMHH. However due to the limited research available, I thought it was important to develop this area of research; to confirm, enrich and understand the challenges and benefits of having a family member in a FMHH.

1.7 Aim Of Study And Research Questions

There is a need for current research within England that explores families' experience of having a family member in a FMHH. For qualitative research in this field to be credible it requires a sound methodological and analytical process, which the current research aims to achieve. Prior research does not consider families' experience in relation to existing conceptual frameworks regarding "caring" for a family member with a MH difficulty; this research aims to apply and critique the three most relevant conceptual frameworks to initiate the development of a more theoretical understanding of families' experiences.

Further research that explores families' current needs and "burdens" would be helpful in bringing this research up to date, as would exploring whether families perceive any benefits to the SU's FMHH admission previously not considered, giving rise to the first research question; in what way(s) does having a family member in a FMHH benefit and/or challenge the family?

Research that focuses on the experience of the 'family', as opposed to "carer-SU" experience, previously centred on the mother as the "carer", is required in order to think about the systemic family impact as opposed to individualising the experience. Furthermore, research that explores the dynamic processes within families, acknowledging that families are not static units that are "burdened" but are families that adjust and change to events and changes within their environment, is required. This research could aid FMHH (or other relevant services) in considering how families can be best supported to achieve positive outcomes. This provides the rationale for the second research question; when a family member is in a FMHH, what may change in the family?

Moreover, research that explores and identifies what internal and external resources families use to support their family and their experience of these, would be helpful in a number of ways, including understanding the ways in which families cope and seek support. The third research question is therefore; what resources are used by the family when a member is in a FMHH?

This exploratory research could also identify whether the current legislation and guidelines regarding families' involvement in SU care and whether in receipt of family support from FMHH are being put in to practice. Ideas generated from this research could support ways in which FMHH could consider the relevance and appropriateness of their current service provision for families and adapt, or implement new, support structures.

The aim of this present study is to generate rich exploratory data of families' experience of the process of change when a family member is in a FMHH.

To address this, the three primary Research Questions are:

- In what way(s) does having a family member in a FMHH benefit and/or challenge the family?
- 2. When a family member is in a FMHH, what may change in the family?
- 3. What resources are used by the family when a member is in a FMHH?

2.0 METHODOLOGY

This methodology details the rationale for qualitative methodology i.e. thematic analysis (TA), the study's epistemological and ontological position, a description of the design used, quality assurance and ethical considerations.

2.1 Rationale For Methodology

A cross-sectional qualitative interview method which sought to generate rich exploratory data of families' experience of the process of change when a member is in a forensic mental health hospital (FMHH), was employed.

Qualitative research was thought suitable as it aims to enhance understanding of human experiences and processes (Harper & Thompson, 2012).

2.1.1 Epistemological And Ontological Position

Willig (2013) states that the assumptions created by the research question and the authors role in relationship to the research should be acknowledged before the attempt of clarifying the method of data collection and analytic process. The research questions and rationale for these set out in the Introduction, demand the study to take a Critical Realist position. Critical realism is ontologically realist (i.e. there is an assumption that there is an external reality that is independent of human minds) and epistemologically relativist (i.e. different methods produce different perspectives on reality). The study aims to gain knowledge of what is 'really' going on in the world but acknowledges that the data gathered may not provide direct access to this reality.

A critical realist approach to research assumes that data is informative of reality, but does not straightforwardly mirror it - rather it needs to be interpreted to provide access to the underlying structures of the data (Willig, 2012). In other words, although a reality exists, it is only 'imperfectly apprehendable' (Guba & Lincoln, 1994). In this study, for example, interviews are conducted with family members. The interview data reflect that person's perspective (which is also influenced by demand characteristics associated with interviews) and the analysis is an interpretation made by the researcher who constructs the findings based on their own understanding, experience and knowledge, so the analysis

is constructed by the lens in which the data is viewed. Moreover, we cannot expect families to know the underlying mechanisms for how their families may change or conditions that inform their experiences of having a family member in a forensic mental health hospital (FMHH).

2.1.2 Rationale For Critical Realist Thematic Analysis

The method of qualitative analysis needs to be compatible with the epistemological position (Willig, 2013). Thematic Analysis (TA) was selected – this is a method of identifying, analysing, organising, describing, and reporting themes found within a data set (Braun & Clarke, 2006). According to Braun and Clarke (2006) it can be conducted from different epistemological standpoints (e.g. realist, social constructionist, phenomenological etc).

There are relatively few studies exploring families' experience of the process of adjustment and 'recovery' when a family member is in a FMHH, thus this research is exploratory. TA was thought to provide the most useful methodological framework as theories can be applied to it flexibly (Braun & Clarke, 2006; Clarke & Braun, 2013; Willig, 2013) without single a-priori theoretical assumptions about what may be learned from the data (Willig, 2001). The researcher is able to interpret individuals' accounts of their experiences and remain close to them. TA is useful in examining individuals' perspectives, highlighting similarities and differences, and generating unanticipated insights (Braun & Clarke, 2006; King, 2004). Practically, TA structures the handling of data, enables a summary of key features of a large data set, and supports production of a clear and organised report (King, 2004).

An inductive approach, was undertaken to capture and identify patterns within the data, in order for themes to be driven by, and strongly linked to, the data (Braun & Clarke, 2006; Patton, 2015), in line with the epistemological position. However, to claim a purely inductive approach would be naïve as themes do not directly represent the spoken word (Banister et al., 2011) or 'emerge' from the data, but are actively constructed by the researcher, informed by the literature and the author's experiences, beliefs and assumptions (Taylor & Ussher, 2001).

Grounded Theory (GT: Glaser & Straus, 1967) was considered as an alternative method of analysis. However, GT is a method that enables the emergence of a

theory from the data, specific to context. Therefore, the development of the theory does not rely on analytical constructs, categories or variables from pre-existing theories. As there are so few studies found from the literature search, the aim was to conduct an exploratory study. GT is more useful when there is more of a possibility of developing a theoretical model. Moreover, GT focuses on social processes, however in this study only one family member was interviewed and so a GT model would be limited.

The study was not focused solely on developing a rich description of each person's subjective experience as in phenomenological studies. Although the research questions aim to produce knowledge about human experience, they are not specifically concerned with producing knowledge about the subjective experience of the participants i.e. their feelings, thoughts and perceptions which constitute their experience i.e. a phenomenological position, the research questions demand an understanding of what may give rise to these experiences i.e. context (social, political, cultural, systemic, relational, psychological). Moreover, this study included the clarification of participants' views and opinions as well as subjective experience. TA was favoured because it enables the researcher to interpret the person's experience and the context in which these experiences arise. Moreover, TA is primarily focused on patterns of meaning across data sets, as opposed to the participants' individual experiences', enabling the analysis to make generalisations about the cohorts "reality".

The study was not aimed at developing an understanding the social and/or discursive construction of phenomena nor at focusing on the language used by participants as in social constructionist discourse analysis. As a result, Discourse analysis was not an appropriate method.

2.2 Design

The research protocol can be seen in Appendix B.

2.2.1 Development Of Interview Schedule

Semi-structured interviews enable participants to speak freely, reflectively and develop their ideas (Smith, 1996), within a focussed but flexible framework of questions. Such interviews may create biased responses as the discussion will

be shaped by the questions, societal conventions of topics and the participants' interpretation of what the interviewer wants to hear (Hammersley & Gomm, 2008). Participants will only give what they are prepared to reveal about their experience, but the semi-structured nature allows for this flexibility and will be considered reflexively. Semi-structured interviews are more conversational than structured, thus difficult to replicate, but they do provide opportunities to elicit rich relevant material from participants.

The first draft of the interview schedule was developed after an initial literature review and co-developed with clinicians who work with families in FMHH, to consider the tone, language and any inherent assumptions made (Appendix C). A pilot interview was conducted with a colleague to ensure that proposed questions promoted 'natural' conversation. A second pilot interview was subsequently held with the initial participant; the language and question structure was adapted, and further prompting questions added (Appendix D).

2.2.2 Research Setting

High, medium and low secure FMHHs situated in two different NHS Trusts in England were used as recruitment sites, and participants were recruited from a medium and low secure hospital. These hospitals have various levels of family and carer engagement including carer support groups, family therapy and family network days. The research team included myself (Chief Investigator (CI) and interviewer), Clinical Psychologists or Family Systemic therapists (Local Collaborators (LC)), all working with SU and their families.

2.2.3 Resources

The research required: a dictaphone, encrypted computer hardware, transcribing equipment and a mobile phone. Travel expenses were reimbursed (maximum £15) when a receipt was provided. An agreement with services to use interview rooms was made. No staffing costs were incurred. Any training required e.g. 'Key Induction' was covered by the NHS trust once an honorary contract from the organisation was granted.

2.2.4 Recruitment

2.2.4.1 Identifying and recruiting participants

- Once ethical approval was granted by the NHS Research Ethics
 Committee (REC), Health Research Authority (HRA) and Research and
 Development teams (R&D) in the NHS Trusts, the CI requested that LC
 identify 'suitable' families.
- Local Collaborators verbally requested permission from the SU for their families to be contacted regarding the research. This was recorded on the SU medical notes.
- 3. Local Collaborators sent invitation letters to the families identified, informing the family of the research (Appendix E: Covering letter, Appendix F: Information Sheet, Appendix G: Contact Details Form, stamped addressed envelope). The family were asked to self-select one or two members to be interviewed. It was understood that different perspectives could be offered by individual family members within one family and it was important to capture these, however, it was considered that holding more interviews with different families, could potentially increase the breadth, if not the depth, of themes.
- 4. Families contacted the CI to inform of their willingness to take part in the research, via stamped addressed envelope or a telephone call.
- If the CI did not have phone contact at stage 4, the CI contacted the family via phone to set up the interview. A confirmation letter (Appendix H) was sent.
- 6. If families did not contact the CI within eight weeks of the 'invitation' letter, it was assumed that the family did not want to participate in the research and there was no follow up.

2.2.4.2 Inclusion Criteria

Adults (18 years or older) who identify as family e.g. parents, grandparents, siblings, neighbour, friend, foster mother etc. to a SU in a FMHH. Children of SU were not explicitly sought as it was assumed that the child and SU have a different quality of relationship than with their family of origin i.e. sibling, parents, and use of such data would reduce the homogeneity of the sample

Able to read and speak English. This criterion was included because of financial

constraints and the practicality of getting interpreters as visitors into FMHH. Additionally, it was thought that non-English speaking participants may have a different experience of having a family member in a FMHH to English- speaking families because of the additional language barrier.

Family member resides in a FMHH and has agreed to their family being contacted for research purposes. This criterion was thought important to ensure transparency i.e. to reduce secrecy and potential friction in families.

Family members have: 1) a form of contact with the SU and are involved in their support system, e.g. visits the SU, attends care meetings, attends family therapy at FMHH. 2) are known to have a relationship with the forensic service i.e. some form of 'family intervention' and have a dialogue with the SU clinical team. This criterion was a necessary pre-requisite for the LC to be able to identify 'suitable' families.

'Suitability' was based upon the clinical judgement of the LC and SU clinical team and was loosely defined as a family (not including SU) where no imminent risks were identified in relation to their mental health (MH) or risk to self or others. To reduce the risk of the research negatively impacting upon families and their relationship with the hospital, the LC considered the likelihood of family members becoming distressed by the interview questions. 'Suitability' of participants was understood to fluctuate as it was dependent on family context, and it was therefore paramount that the SU family was known to FMHH and that the CI and LC communicated regularly.

2.2.5 Data Collection And Analysis

The sampling method was purposive; eleven interviews from nine different families were held, this sample is an appropriate number for qualitative analysis (Guest, Bunce & Johnson, 2006). The interviews took place from December 2017-March 2018.

2.2.5.1 Data collection

 The interviews lasted no longer than one hour and forty-five minutes. At interview the CI discussed the Participant Information Sheet and gained Consent (Appendix I). The participant was asked to fill out the short Demographic Questionnaire (Appendix J). Prior to the start of the interview the Debrief Information Sheet (Appendix K) was discussed, a precaution should the interview be terminated early. The interview then proceeded using the Interview Schedule (Appendix C/D) and was audio-recorded.

- 2. At the end of the interview participants were reminded of the Debrief Information Sheet (Appendix K) and were given an opportunity to ask further questions. If the CI identified risk issues (i.e. disclosure of significant risk to self or others) the participants were informed that the confidentiality agreement would be breached and the LC notified.
- 3. The CI informed the LC of any potential risk, who then called the participant and encouraged them to seek help via the GP or police.

2.2.5.2 Demographics of participants

Twenty-three 'suitable' families were identified, of these, 13 SU gave consent to contact their family. Eleven family members from nine families responded to the initial letter and provided informed consent (see Table 2: Demographics of Participants and Family Context).

All SU were male i.e. sons of the participants, whose age ranged between 21-40 years. They had varied journeys before being admitted to FMHHs (see Table 2, column 8). Within four of the families' the SU index offence was violence against another family member, three of these were against the mother. It was not disclosed whether the SU had been physically violent to members of the remaining five families.

Table 2 Demographics of Participants and Family Context

Participant	Age	Ethnicity	Religion	Occupation	Number of Children	SU violence to family	SU involvement with service	Type of FMHH
Mother1	67	British- Pakistani	Muslim	Retired	4	Yes	2 admissions to same FMHH across 7 years. Current admission 2 years. Community Mental Health Team (CMHT) contact prior to admission. No known prison contact.	Medium Secure (MSU)
Mother2	50	Caribbean	N/A	Working full time	1	Unknown	3 admissions to same FMHH. Unknown contact with MH services/prison prior to admission.	MSU
Father3 (married to	72	White British	Christian- Church of	Retired	4	Unknown	In an out of general MH inpatient for 10 years, one of which was MSU for a	Low Secure (LSU)

Mother 6)			England				year. Current admission 1	
							year. No prison contact.	
Mother4	43	White	Christian-	Working full	3	Yes	Inpatient in general MH	LSU
		D ''' 1	Church of	time			hospital 6months. CMHT	
		British	England				contact prior to admission.	
							Prison 3 months, MSU for	
							1 year. LSU 1month	
Mother5	71	Afro-	Christian	Retired	1	Unknown	In an out of general MH	MSU
		Caribbean					inpatient for 20 years	
							across the country one of	
							which was MSU, current	
							admission at MSU 3 years	
Mother6	67	White	Christian-	Retired	4			LSU
(married to		British	Roman					
Father 3)			Catholic					
Father7	51	White	Christian	Working	2	Unknown	In and out of general MH	MSU
		British		part-time			hospitals for 14years. 1	
							year in current MSU. No	

							contact with prison.	
Mother8	63	White British	Christian- Roman Catholic	Not working due to health conditions	3 biological 3 step- children	Yes	Prison 1 year followed by 9 years MSU and 5years LSU	LSU
Mother9	63	Black British	Christian Pentecostal	College	7	Yes	In and out of prison for 1-2 years. Current admission 2 years.	MSU
Father10	70	White British	Christian	Working part-time	2	Yes	In and out of prison for 3 years, followed by 1 year MSU (out of area). Current admission 6months.	MSU
Mother11 (married to father 10)	56	White British	NA	Unemployed	2			MSU

2.2.5.3 Transcription

All interviews were transcribed by the author using a simple transcription method as TA does not require a detailed transcribing convention (Braun & Clarke, 2006).

2.2.5.4 Phases of Thematic Analysis

The six-phase guide of TA detailed in (Braun & Clarke, 2006) was used to analyse the data. Although the six steps are presented as distinct and linear, it is a developing reflective process, involving a constant moving back and forward between phases.

- 1. Familiarisation with the data: The author familiarised themselves thoroughly with the data; listening to audio-records and reading and rereading the transcripts noting any initial analytic observations.
- 2. Generating initial codes: Whilst holding the research questions in mind, pithy labels were generated from important features of the data (Appendix L: Coded extract). Codes were generated at the semantic and latent levels of analysis (Braun & Clarke, 2006). The research journal enabled the research to be reflexive at the latent level (Appendix M). A coding framework was produced (Appendix N) with codes and related extracts.
- 3. Searching for themes: A theme is a coherent and meaningful pattern in the data relevant to the research question. This was an active process, themes were constructed based on any central or unifying features or salient patterns across the data set, producing a set of initial candidate themes (Appendix O).
- 4. Reviewing themes: Involved checking that themes were consistent and reflected the coded extracts and the full data-set. The author defined the nature of each individual theme, and the relationship between the themes (Appendix P).
- 5. Defining and naming themes: undertaken with stage 4, involved writing a detailed analysis of each theme (Appendix Q).
- 6. Producing the report involved providing a clear, coherent and noteworthy account of the data within and across themes; vivid excerpts were used to capture the essence of the theme.

2.2.5.5 Use of a Thematic Network

In conducting this study, the concept of a thematic network (Attride-Stirling, 2001) was utilised in order to present the themes generated from the TA and illustrate their relationship to one another. Thematic networks can be used as an analytical method in its own right, as Barkway, Mosel, Simpson, Oster and Muir-Cochrane (2012), use to explore consumer (SU) and "carer" consultants' experiences and perceptions of their role, in a MH context. In this study, however, it is used simply as a heuristic utilised in the Thematic Analysis rather than a separate method. The analytic categories utilised are as follows and examples are drawn from Barkway et al.'s (2012) study to illustrate:

A 'Global Theme' is a super-ordinate theme that encompass the principal metaphors in the data as a whole. Global Themes groups the lower-order themes i.e. 'Organising' or 'Basic'. For example, 'consumer and carer consultants' role identity".

Where needed, an 'Organising Theme' is middle-order theme that organises the 'Basic Themes' into clusters of similar issues. For example, 'role motivation' 'role preparation' 'role practice/focus' and 'role ambiguity/conflict'.

A 'Basic Theme' is the lowest-order theme derived from the data, in this case the themes generated by the Thematic Analysis. For example, the organising theme of 'role preparation' had two basic themes of 'education' and 'support'.

2.3 Quality Of Research

2.3.1 Trustworthiness

Qualitative research should be conducted rigorously and methodically to yield meaningful and useful results (Attride-Stirling, 2001). 'Trustworthiness' is valued within qualitative research, as it confirms the findings are worthy of attention (Lincoln & Guba, 1985). Lincoln and Guba (1985) refined the concept of 'trustworthiness' using the criteria of credibility, transferability, dependability, and confirmability, to parallel the conventional quantitative assessment criteria of validity and reliability. Nowell, Norris, White and Moules (2017) provide a framework for these criteria to ensure 'trustworthiness' during each phase of TA, which was adopted in this study.

2.3.1.1 Credibility

Credibility refers to the plausibility of the research findings and depends on the evidence presented i.e. can be recognised by the reader (Guba & Lincoln, 1989). This study addressed credibility using techniques of; prolonged engagement with the data, persistent observation, peer-debriefing with the author's supervisor and examining referential adequacy by checking the preliminary findings against the raw data, suggested by Lincoln and Guba (1985).

2.3.1.2 Transferability

Transferability refers to whether the findings can be generalised. However, within qualitative research it is not always known where the findings may be transferred, therefore thick descriptions (Appendix Q) of themes are required, so that those who seek to transfer the findings can do so (Lincoln & Guba, 1985).

2.3.1.3 Dependability

Dependability requires the research process to be logical, traceable, and clearly documented (Tobin & Begley, 2004). An audit trail evidences decisions and choices made by the researcher regarding theoretical and methodological issues (Koch, 1994). Keeping records of the raw data, field notes, transcripts, and a reflexive journal can help researchers systemize, relate, and cross-reference data (Halpren, 1983).

In this study the author stored transcripts in well organised archives, kept records of data field notes, used an accessible coding framework (Appendix N), noted the development of code generation, diagrammatically noted the connections between themes (Appendix R), kept detailed notes about the development and hierarchies of concepts and themes (Appendix P). A reflexive research journal (Appendix M) documented the logistics of the research, methodological decisions, rationale, and the author's personal reflections (Lincoln & Guba, 1985).

2.3.1.4 Confirmability

Confirmability is concerned with establishing how the researcher's interpretations and findings are clearly derived from the data (Tobin & Begley, 2004), it is established when credibility, transferability, and dependability are all achieved (Guba & Lincoln, 1989).

2.3.2 Reflexivity

As noted, the author's experiences, values, assumptions and beliefs will shape how they connect with the literature, read and interpret the data (Clarke & Braun, 2013). To ensure the credibility of the analysis and research process as a whole, transparency and reflexivity about pre-existing relationships with the subject matter are pertinent (Willig, 2013). Reflexivity is important when using a critical realist approach in research as it is not truly objective, although better when participants' and researcher's subjectivity is acknowledged (Clarke & Braun 2013).

2.3.2.1 Statement of position by the researcher

I consider myself to be a "carer," caring for family members with complex mental and physical needs. In this role, I am frequently awash with complex emotions e.g. guilt, anger, resentment, denial, and question how other families who experience so much pain and distress adapt to their experiences. I am passionate about Carers' rights and believe more should be done to support "carers". Similarly, to other scholars e.g. Heim Stierlin, who views the "family as the patient", I believe families should be seen as a whole rather than in parts.

My experiences contributed to my career choice in forensic mental health and I have prior experience of working with men in high and medium FMHH in England. This enhanced my understanding of MH and criminal justice systems, and their inadequacy in involving families in SU care and in supporting "carers".

2.4 Ethical Considerations

The considerations outlined below were carried out in line with guidelines from the British Psychological Society's (BPS) Code of Ethics and Conduct (BPS, 2009) and the NHS HRA guidelines. Ethics approval was sought and gained from a NHS REC and HRA (Appendix S/T).

2.4.1 Informed Consent

An Information Sheet was given to all potential participants. Participants provided signed consent before being interviewed, and were reminded of their freedom to withdraw during, and up to four weeks after interviewing. Data management and the recording of interviews was explained.

2.4.2 Anonymity

Identifying features were altered in transcripts and participants were given an identification number for thesis extracts and future publications, protecting all family members and the services with which they had contact. Where the interviewee requested that a response remained confidential, this was respected. Only, the CI, supervisors and examiners have access to full anonymised transcripts.

Participants were assured that information would not be disclosed to their family member in hospital or to hospital staff.

Anonymity was only compromised if the interviewer had concerns about anyone's safety; in which case procedure, around breaching confidentiality was followed (see 2.2.5.1 points 2/3).

2.4.3 Data Management And Storage

The Data Protection Act 1998 was complied with using a detailed management and storage plan for all data, for example, data was stored on encrypted and password-protected files, secured on university or NHS server/computer/VPN (i.e. not on a personal laptop).

Personal contact information was destroyed once the interview was conducted, except when a summary of the final analysis was requested. Following examination of the doctoral thesis and acceptance, (approximately August 2018) audio-recordings, consent and demographic information will be deleted/destroyed. Anonymised transcripts will be kept for up to three years after the research has been completed and then deleted.

2.4.4 Wellbeing Of Families And Debrief

To reduce the likelihood of recruiting distressed participants, families perceived as 'suitable' were recruited by clinicians who knew them in a therapeutic capacity. Specific questions about SU offending behaviour were not asked, to reduce the likelihood of re-traumatising participants. All participants were given a Debrief Support and Information sheet (Appendix K). A distress protocol was developed and followed by the CI to prevent or minimise harm and respond if necessary (Appendix U).

2.4.5 Risk To Interviewer

As part of the distress protocol (Appendix U), risks to the interviewer were considered. Participants may have assumed that the interviewer was aligned with health and social care services, and perceived this negatively. Recruiting participants considered 'suitable' reduced this risk, as did communications between the research team and the CI compliance with the FMHH policies and procedures.

3.0 ANALYSIS

This chapter presents an account of themes generated from the data collected during interviews concerning families' experience of adjustment when a family member is in a forensic mental health hospital (FMHH). Data was analysed thematically, using the steps described in the methodology. A thematic network organised the themes in to a hierarchy of basic, organisational and global themes, see Table 3.

Table 3 Themes

Global	Organising	Basic			
1.Negotiating systems: "Grappling in the dark" 2.Family processes: "That's what families do"	Families	Challenges of interacting with systems: "A lifetime of struggle" Impact: "They add to the suffering" Services support for families: "What support?" Families are different: "My situation is different" 'Loss' of a family member": "Like a			
families do"	fragment: "It's tearing us apart" Holding the family together: "I've had to	bereavement in some way" 'Loss' of family coherence: "We will be going forward happily and thenstop." Other family transitions: "I was put in intensive care" Holding the families' relationships together: "You put on a brave face"			
	learn to counsel	Keeping the service user within the family: "I forgive you"			

my children"	Parental duty: "I'm his mum"
	Factors that influence families' ability to
	adapt: "Just keep going"

3.1 Introduction To Themes

3.1.1 Global Theme 1: Negotiating Systems

This theme describes families' interactions and experiences with health, mental health (MH) and criminal justice systems (CJS), resulting from the Service User's (SU) complex and lengthy involvement with services. Families faced numerous challenges in contact with these systems; these had significant emotional and practical impacts on the family and their beliefs about services which in turn, impacted the way in which they related to "the system".

Families needed to negotiate systems to meet their own needs, these services were lacking. Appropriate services were suggested by families.

3.1.2 Global Theme 2: Family Processes

This theme recognises that families differ, as do their relationships with the SU. Families changed as a result of the SU MH, violent behaviours and associated admissions to services. Families fractured in different ways and became unable to transition as a family together. Irrespective of whether they fractured or the extent to which they fractured, families attempted to remain connected. Families' abilities to adapt to challenges were influenced by different coping strategies.

3.2 Theme 1: Negotiating Systems: "Grappling In The Dark"

3.2.1 Challenges Of Interacting With Systems: "A Lifetime Of Struggle"

Families faced multiple challenges in accessing MH support for their child and throughout their child's journey, including; navigating and adapting to complex systems and bureaucratic hurdles, accessing and communicating with health professionals, inadequate involvement with SU's care and treatment concerns.

Families found it difficult to access appropriate support for their child when initially unwell e.g. Father3. Some families faced this many times when their son was discharged and then re-admitted. For some, MH/FMHH support was directly accessed, whereas others understood prison was inappropriate and wanted their child transferred to a FMHH e.g. Mother4.

Father3: We had quite a problem umm with getting someone to see <SU>, you know a psychiatrist [...] they needed to get him in hospital and then that took a while [...] he went into <hospital1>, they found him a flat in <location.[...]back into hospital [...] found a place in <location> back into hospital(2)[...]nothing was moving on so they sent him to <hospital3>[...]then he moved to <FMHH>. (63)

Mother4: I didn't think he should be in prison because he wasn't well. You know and someone in that mind I just thought would be unsafe in prison. (189)

Families had to learn how to navigate complex systems and the disjointed service provision.

Father10: I work in the health service but there is no way we could get the help we needed even though we know the way, you see, [...] "the people out there that need the help badly but have no knowledge of how the health service works, it's absolutely hopeless". (458)

Families felt powerless in the system but some learned ways of resisting and working to achieve positive change for the SU.

Mother8: That was heart breaking because as I thought there was nothing I could do. But as you put your mind down to it, do a lot of research which I done, you can do something, and I did do something with the help of local government and this lady in the government I did get him moved over (prison to FMHH) and I did do what was best for him. (57)

Families learnt how to manage changes within and across services e.g. adapting to ward cultures, staff changes.

Mother5: I get my information from the social worker [...] there have been so many changes... (91)

Mother2: I have occasionally been to ward rounds umm but it took me a while to realise, yes, you can get to ward rounds and be invited, and different teams operate differently, that's always a bit of a hurdle or sometimes calling a meeting. (286)

Families faced challenges in communicating with FMHH, particularly accessing staff and information, and the methods of communication and language that FMHH used.

Families considered services offered scant information about; service structure, care pathway, SU's care and general MH knowledge e.g. treatment, prognosis, the Mental Health Act. Some felt that information was deliberately with-held.

Father3: Basically, we found it very hard to get information, umm his care co-ordinator they wasn't very engaging, we were just stuck on the outside of it. (211)

Accessing health professionals was difficult and, when contact was achieved, families complained of their insensitivity, or the technical/medical language used.

Mother9: They say the first stage is to contact the social worker. And it is from the social worker you can book to see the psychiatrist in charge, but you can't get <Social worker>. It's a horrible vicious circle, it's a hurdle. [...] it's not possible to make progress and there is nowhere you can go to. (384)

Mother6: ...other times you know the receptionist can be quite grumpy and rude or even blank you – that affects your experience and then if the staff

are uncommunicative – sometimes the staff just don't talk to you, so it's a silent walk to the ward – that can be difficult. (77)

Mother9: They (staff) think you are ignorant and you're empty and that you wouldn't understand that you have no knowledge that kind of thing. You know they think they can come out all of this medical jargon that we wouldn't understand, but if we didn't understand I would get my dictionary and I will have a look or have a google [...] but they seem to treat you like a ... grown up child... (587)

Some families reported that services communicated in a dehumanising and unhelpful manner e.g. letters, texts, brief phone calls, without introduction. Mother4 described the difficulties of being both a victim, overcoming physical injuries, and a mother, caring for her children. She was told via text to attend court to give evidence about her son, and of the trial outcome, without any support.

Mother4: I got notification of the court case, via a text message. [...] The court services. Actual victims' services, the people at the court that you liaise with, they sent me the text to say that I would be required to attend court [...] So that actually just threw me because then I'm thinking oh my God I can't, I can't do this as well...they sent me a text with the court findings as well. (207)

Some families felt included in meetings (ward rounds, CPA, tribunals etc.) regarding SU care. However, most described a lack of involvement in decision-making around SU care, despite wanting this.

Mother8: Well they made me very welcome. And they talked about <SU> and what he is doing and how he is progressing since his last meeting [...] Have I got any goals that I want him to meet. They did bring me into the meeting I wasn't just there listening to it, they did bring me into it. (142)

Mother9: Yeah, because when they are facing a tribunal they should have their parent there, whoever, to give their support. (349)

Reasons for lack of involvement included: the hospital's distance from home, SU aggression towards parents and lack of invitation.

Families were aware of the hierarchy of treatment options available to the SU, with medication being the most important. Families considered such treatment as temporary and non-holistic, and wanted to collaborate in SU care.

Father7: The psychology isn't seen as important as the medication when really they ought to be psychosocial approach. I mean that's what they say at the <FMHH> [...] but maybe the reality is somewhat different. (466)

Mother5: Because only medication isn't going to help. He just blocks everything. <SU> dad told me that he is very good at chess. <SU> wouldn't have to know, but if we (family & clinicians) sat down and said why don't you try him with this with others, try what he likes. (412)

Mother6: ...his mum, dad and siblings are an integral part of that (care) but there seems to be this disconnect (between FMHH and families) and we have to really got to get back on track. (328)

Mother1: Yes, that's all we want to do is help. (598)

Families faced bureaucratic hurdles concerning consent and confidentiality, when seeking MH treatment for their child, information-sharing and involvement with SU care and visiting.

Mother9: What is he here for!? What are they doing to him? "Oh sorry, we can't speak to you because..." And then I got in touch with the social worker "oh I'm sorry I can't speak with you because you know you need his consent". Somebody talk to me please!? There was just nothing for over a year (whilst at FMHH) I have never had one person say to me oh this is what is happening with <SU>. Absolutely nothing. (272)

Mother11 described the frustrations many families' experienced when their adult child had withheld consent from treatment. Prior to FMHH admission families felt ignored, given that they had informed clinicians of the SU risky behaviour.

Mother4: <SU> had been referred to the mental health services before he got some problems, I had got the police to take him to the hospital and they got a psychologist to speak to him, he said he needs referring, <SU> refused to go. I kept going back to the doctors and this went on for about a year and half before he got sectioned. It took that long just because he's an adult, what can we do? (313)

When family members were not invited to meetings about SU's care they did not know whether this resulted from SU non-consent, FMHH incompetence or whether they were being ignored.

Mother2: They have been fine but I generally don't get invited to them but I think that is because more down to <SU> rather than the team and then he tells me the day before and then I can't come because I have work. (327)

Service's policies and procedures needed to be understood and followed by families; this presented challenges.

Father7: Well the fact that they are locked up. There is a kind of strict procedure there. Visits end at 8 o'clock. Have to be able to book a visit. You aren't allowed to bring things in. (223)

Mother9 described initial relief in knowing her son was in a FMHH rather than prison and then being confronted by bureaucratic visiting procedure.

Mother9: There was a sense of relief that the matter was over, but I don't know where he was (not informed of transfer from prison to FMHH) ...so there was a bit of relief. [...] so I knew where he was, so you know that was relief. So, then I wanted to go and see him, then there was this hurdle of [...] trying to get to see him. (236)

Many families spoke about the FMHH imposing and prison-like physical infrastructure e.g. small spaces, and witnessing distress of other SUs, as traumatic. Two participants used 'cage' imagery in describing the SU environment.

Mother9: There was actually a time and I wanted to see <SU> (in prison) and they then said to me you have to come and see him and there was a place that looked like a cage, you have to come there because he has been aggressive and I thought, oh no! Then when I got there that wasn't <SU>! So they had got him mixed up with someone else. So you can imagine the trauma of thinking that he is caged in the first place and then when you got there it wasn't even him, it was hell. (204)

Father3: We used to go and see <SU> (at FMHH) and they were just walking up and down liked caged animals like in the zoo like caged animals. Pacing up and down [...] Well yeah it is quite difficult. (103)

3.2.2 Impact: "They Add to the Suffering"

The impact of the challenges faced were considerable. Families wished that MH treatment had been secured promptly for the SU, in order to lessen or prevent their violent behaviour, and/or endure the challenges of negotiating systems, a "lifetime of struggle" (Father7, 274). Families required persistence when accessing support for, or information regarding the SU, used available resources, and described themselves as "fighting" the system. Some families expressed relief and hope regarding their child's admission to a FMHH; others were concerned.

Many families felt 'blamed', i.e. that services considered them responsible for the SU's situation and deliberately distanced them from SU and the FMHH. Consequently, families felt painfully disconnected from the SU, powerless, devalued or unrecognised by services and lost trust in systems.

Families reflected that should earlier appropriate support have been accessible to their son, their lives would have been less traumatic. Mother1 referred to her son's second admission to a FMHH; his offences included violence towards her.

Father10 referred to the deep pain his family suffered in prosecuting his son, following violence against them.

Mother1: So, in the beginning if he had got the treatment he would have been better and it wouldn't of come to this, that's why. (390)

Father10: We had one court case and she (grandmother) went and saw the judge and said [..] "He is my grandson and I don't want to do this". It's been unbelievably bad; you have no idea how bad we feel. (313)

Persistence in seeking appropriate provision, chasing information and contacting services impacted on families' capacity and resources.

Father3: Well you spend all your time and hours trying to chase these people, its tiring. (228)

For some families, persistence was associated with a sense of purpose and compensation for felt their powerlessness towards "the system".

Mother2: I make sure I am present, you know don't think you're not going to hear from me, I am going to phone once per week, I want answers once a week and I'm going to ask questions, I'm here. That's my way of dealing with it. (228)

Families experienced a "battle" in advocating for their son e.g. Mother9. Mother8, like others, used her knowledge and resources as she "pushed for" the SU's appropriate support. Neither time nor number of admissions eased families' struggles e.g. Mother2.

Mother9: At each stage, you won this battle and then the next stage you're back is against the wall again. (160)

Mother8: I pushed for the process to go through (to be transferred from prison to FMHH) and I used my local MP as well... (31)

Mother2: It never feels easier, no. I feel better able to cope in some respect but it never feels easier because it's still a loss of a loved one isn't it? and it's the notion of why they are going away, which is about an illness that has to be managed, it's not the kind of illness that you kind of take a pill and it suddenly makes it better and it goes away. (82)

Families described pain and disconnect from the SU and a reduced sense of purpose, resulting from non-inclusion in SU care. Some families felt such exclusion was intentional. This, and some aspects of FMHH procedure were considered to intrude on family privacy, resulting in feeling powerless.

Father3: We were (family) just stuck on the outside of it. (212)

Mother4: ...we were just kind of left, left like at the end of the hook sort of thing, nobody tells ya a thing until. (481)

Mother9: I don't understand it. If it's an intentional thing that they don't want to include us. (356)

Families felt powerless in relation to the dominating systems. Mother11 believed her role in SU care was minimal because the FMHH dictates the "care" process.

Mother11: There is very little you can do when they are in services is there? (404)

FMHH were viewed as invasive to family life, e.g. the way in which clinical interviews were undertaken, although some in this context thought it helpful to the SU.

Mother8: Two ladies come here might be about a year and half ago to speak about <SU> [...] I was like this is nothing to do with anyone else [...]. Didn't know what it was all about and haven't heard a word since [...] I thought it was pretty stupid if you are going to take someone's time and sit and talk to them... (153)

Perhaps because of lack of contact or sense of connection to the FMHH, families perceived staff as exceeding expectations or lacking compassion.

Mother4: I was quite surprised that a doctor would bother (to visit parent at home). (167)

Father7: The <clinician> is often very good, seems to be in it more for themselves than for the client. They get a good life and get a good salary and they get the feeling that they are helping people. But as soon as Friday 5 o'clock comes they are woosh out the door. So, you do wonder sometimes whether how committed they are to the patient. (469)

Families members perceived blame from various sources during the SU journey, e.g. from police and health professionals. This may have exacerbated self-blame already held by parents. Some families reflected that this was the FMHH's rationale for not including them in SU care.

Mother8: The police were saying that <SU sister> helped him. The police were trying to vindicate most of the family [...] It was very heavy on us [...] Then they realised that it was all rubbish. (259)

Mother9: They (clinicians) think that I am the one to be blamed, that they think the condition that he has that I have contributed to it one way or the other, so you can't be trusted with it. You're a part of his problem, that kind of thing, like they've got to protect him (SU) from you, that kind of thing. (595)

Families believed they were not recognised by systems, not heard, valued or supported and their trauma not considered. Many described feeling 'non-existent'.

Father7: It is tough having a relative in <FMHH>. I don't think the hospital realise how tough it is to be quite honest (220)

Mother9: There is just nothing in place, it's as if you are just not there. Not there. As if, it doesn't matter about the family, they're not feeling anything, it's not about them, you know the system is such that you might as well not be alive, they don't see you there as being concerned. There is no support. (182)

Two parents felt compelled to threaten services with the media because they felt ignored, and de-valued.

Mother6: I phone, I write and this last episode with him (SU) here [...] nobody had a plan [...] So I then threatened them with the Daily Mail. (232)

Due to their experiences, families' lost confidence in present or possible future systems, felt failed and lacked trust. Some families explicitly lied to by services.

Mother6: <husband> thinks he's failed <SU> and I said you haven't failed <SU>, the system has failed <SU>. We have been failed big time. (266)

Father10: Umm So the police say to us that if you make a statement he will get the help he needs, but it didn't work [...] The police just fed us false hope, that's it yeah, so we went to court, and we didn't get the help. (245)

Mother4: I don't still at that time have much faith in the service. (131)

Families expressed concerns regarding on-going NHS funding, and this reduced trust. Mother8's fear and distrust of her son is compounded by her worries about inadequate funding for him post-discharge.

Mother8: He needs to be watched when he comes out which he'll soon come out of <FMHH>. [...] This worries me terrible. The aftercare I don't know, I don't know if anyone knows if there is going to be enough money in the country to have after care. Where will he go? He is not coming anywhere near where I live. As much as I love him I don't trust him. And I think my trust in him will never be there. (430)

Some parents felt relief when their child entered a FMHH, believing they would be safe and receive appropriate treatment. However, relief was relative to the SU's prior environment i.e. prison, homeless. In contrast, some parents had concerns related to the type of security and length of incarceration in a a FMHH.

Mother8: Just knowing that he was, if you like, in a more safer environment, even though it was a high security, it still seemed to be a safer place to be. (220)

Father7: I mean it's a lot more serious and a lot harder to get out when you are in a forensic set up. There was a sense that it was a serious move. (133)

3.2.3 Support Available For Families From Services: "What Support?"

This theme encompasses service's provision for families, lack of appropriate support and families' suggestions for services. It follows "lack of recognition by services," but is distinct as it focuses on how families wanted to be recognised, in addition to their "caring role".

General support for families included statutory MH services and victim support (via third-sector or probation). This was viewed as unsupportive and referral took time and persistence. Additionally, siblings of SU received counselling from their university. Reasons why families sought psychological support, included a need to voice pain, feel less alone and process previous trauma.

Father7: No. My psychiatrist knows that <SU> is in the <FMHH>. They offer a few platitudes – stuff like that but there is no real support. (398)

Mother1: I had counselling for about 12 weeks. I: In relation to what happened (attack)? P1: Nods. (291)

Mother4: It (Victim support input) just should of happened a long time ago. This should have been there in place, I should of had someone talking to me through the court case, not just get a text message, it should of all been put in place straight away. (336)

Families were ambivalent about Family Network Days (FND) and family therapy service provided for them by the FMHH. Families attended FND to get information, meet clinicians or seek support from other families. Some did not attend because of other commitments e.g. work. Benefits of family therapy (FT) were recognised, some saw it as a difficult process, but many were on the waiting list and hopeful.

Mother6: I was very pleased that the <FMHH> started the family days (FND) to recognise them, and I was surprised that they hadn't done it before. (193)

Father7: I mean they (FND) are ok, but you wonder whether they are just a token shop and nothing else is going to be done...Well I mean it was polite and friendly and that but it just [...] you just wonder whether anything is going to be done. (184)

Mother1: Because it's (FT) a good thing to do to be together and talk out things which we usually don't discuss. (368)

Families sought social support and guidance from third sector organisations via "carers" support groups and helplines; these were considered limited, lacking specificity and therefore unhelpful in decreasing families' sense of isolation.

Mother9: I phoned MIND and they were most unhelpful, there was just nowhere to go. (97)

Mother11: I do go to a support group in <location> people there are lovely, but nobody has their son in forensic services, so I feel that we are the odd one out. (40)

Although, families were resourceful in sourcing support, it was difficult to access, not necessarily appropriate or timely. Families criticised the lack of service support and struggled alone. Mother6 noted that if she could access a statutory carer's assessment, any suggested appropriate support would be unavailable to her. Mother4 commented that if she had received earlier support

her relationship with her son might have been better. She (and other families) believed that once SU were admitted to a FMHH they received appropriate care, but that additional services were needed to support distressed families.

Father10: I fought him off (SU). I fought him off because if you look at me I'm not very big and he got quite violent and I used to have to pull him away from his mum and get away myself [...] but eventually sadly there was one night... We just struggled on our own, we had no support. (168)

Mother6: The Carers' Trust that provided it (the carer's assessment), don't look after mental health because they don't have the experience, because they only look after the elderly and the frail. So even if I had had my carer's assessment I still couldn't access (local authority) services. (361)

Mother4: I think if I had more support then I might have that relationship with him (SU) now, if I had had the support from the services [...] I was just sort of left and it was like, you know since (starting counselling in) January, I've got so much, I feel so much better but if there had been a support there then [...] But there needs to be someone there that supports the victim, to support the families because they're the one that is left, <SU> has got all the help he needs. But the help for the families are not there. And it should of been there since day dot, I shouldn't of had to wait for an investigation to be told it was preventable and predictable. I knew that. (511)

All families spoke of genuine surprise that FMHH staff did not enquire about their well-being. Mother2 described contact with FMHH as being about the SU or services but not about her needs. Mother9, when asked whether enquiries had been made about her, vociferously denied this.

Mother2: I don't think there is ever a meeting point where it is just about you and not about the service or about the patient and I don't think there is ever a time that actually happens. (353)

Mother9: No, to call you up and ask if you're ok???? No!!!! They add more to the pain. (559)

Families believed FMHH should recognise and appreciate their value in SU care.

Mother6: ...obviously for health care professionals, recognising carers have an important role. (354)

Families wanted support for themselves to include; counselling, a space to remove themselves from the "parenting/caring" role and a place to talk to other, similarly positioned families. In addition, they wanted services to provide effective communication, proactively information share and offer relevant psychoeducation.

Mother8: Yeah – a counsellor would have been better. But that would have been nice in the process. But not right at the beginning. (405)

Mother2: I suppose somewhere where you could tap in to resources or maybe a space where you can go, have a cup of tea have a chat or maybe or a space where you could do something. (400)

Mother9: ...there should be effective communication with the parents, but it has to be a continuous thing. (472)

Mother1: They should educate the families on that's an illness and how we (family) can help them [...] somebody in the hospital to talk to the family. (578)

3.3. Theme 2: Family Processes: "That's What Families Do"

3.3.1 Families Are Different: "My Situation Is Different"

Families interviewed varied in relation to size, composition, marital status and geographic distribution. Seven of the eleven families considered themselves 'close' family; others didn't comment on the quality of their relationships.

Father7: Me, then there's two sons (2).

Mother9: Me and <SU>, [...] is one of 7. [...] The first 2 are married with children [...] The family is very close, so we have in- laws. I have sisters. I have 3 sisters; [...] There is still my mum and still <SU>father... (2)

Mother8: We were all very close. First of all, we all still are very close. (28)

The level of SU violence directed towards family members varied across families and over time i.e. the index offence of some SU was violence to the family and this aggression continued; some SU had never been physically violent towards their parents but were aggressive whilst detained in services.

3.3.2 Families Fragment: "It's Tearing Us Apart"

This theme encompasses how families changed as a result of the SU MH and admissions to services. It emphasises that families were unable to transition together because of the felt 'loss' of the SU, relationships ending, members navigating different life paths, unexpected transitions resulting from the SU being unwell, and, expected transitions that families had to adapt to whilst the SU was in a FMHH.

3.3.2.1 'Loss' of a family member: "Like a bereavement in some way"

All families felt that they lost a family member due to the development of MH difficulty, and transfer into a secure service. Families felt powerless in the light of the SU's distress.

Families described a 'loss' of their family member in relation to the duration and deterioration of his MH difficulty, and length of time in secure services. Families did not perceive that services were addressing the needs of their son (lack of MH treatment, not engaging the SU in treatment), so prolonging their loss.

Mother8: When he was in <pri>prison> he couldn't cope at all. His coping himself was closing in, closing down... I could see a big change in him through the months knowing that he would have to be there for a very long time. (50)

Some families spoke of the SU being missed in everyday life. At events that marked family transitions e.g. marriages, births, SU's separation from his family was made more apparent.

Mother2: ...it does change so you realise someone that's with you all the time is suddenly not there. (32)

Mother1: ...they (siblings) were very sad you know especially on Christmas, Eid and other functions when everybody is together like for <son> wedding. They missed <SU> lot. (414)

'Loss' of the SU is metaphorical but 'loss' effectively describes an unexpected painful family life transition. Other families described life lost for the SU, in relation to what they believe he would have achieved in the context of traditional life events. For some the SU's lack of ability to transition meant that families were 'stuck' also.

Mother2: Well under the circumstances suppose it would have been different if he had left home and gone to university or something like that but just given how things happened. I suppose in our particular case it wasn't this you know "let's go and visit the doctor or something" there were other factors that took that decision-making process out of your control. (38)

Father3: Yeah we were stuck... <SU> is not getting any younger... that's what worries me and he was getting older and missing all, he's missing a lot of his life, missing [...] he's getting on now he's in his 30s. The worry is that he's missing out, a job and perhaps getting a family... (156)

Parents reminisced about their child when younger, in contrast to their unwell, adult son. In the context of fear, Mother4 described her son's mental illness and violence as unexpected given her memories of her child. Mother11 reiterated this, in describing her son when acutely unwell, as a person she did not recognise.

Mother4: I'm always going to have that slight fear and think it could happen again. I worry that my younger son's going to become mentally ill, although it's probably you know it's not likely to happen but I look at him and I think you know, could it happen to you? Because <SU> wasn't like that, he was a very loving, calm he was just a nice kid. (304)

Mother11: ...Foaming at the mouth and the rage in his eye, he was just like a different person. (436)

Parents remembered an "idealised" child; this could be interpreted as their difficulty in acknowledging current circumstances and resisting change.

Associated with the felt 'loss', parents described feeling helpless, unable to reduce their child's distress or control unpredictable symptoms. In respect of 'parental norms' parents felt they should have been able to manage the responsibility of caring for their child, but that this had been devolved to the system. Parents' lack of self-efficacy and mastery were overcome through persistence and resourcefulness (see "negotiating systems") maintaining a sense of their parental role.

Mother2: I suppose it's quite debilitating isn't it as a parent I'm speaking of that perspective um and I think that's the whole thing about this whole episode that you kind of feel, you do feel very much out of control. And that you have no control and then there's this notion as a parent your meant to be responsible for and your supposed to care for and your supposed to fix everything, it's a situation you can't fix and that just its quite mind blowing suddenly. (59)

A few families described their acceptance of the SU's MH and their life within a FMHH, submissively; associated with the length of time their son had been unwell, and time spent in hospital without apparent progress. In these cases, their sons had been in services for over 10 years. Other parents were less accepting of the SUs' current MH and hoped for SU "progress".

Mother5: At first I thought he would get better, at first. I used to tell his dad and give him a lot of hope, that one day he will get better. But then I realised it's just a pattern and this is the way, it could be I accepted it more. (280)

Mother5 described how her earlier positivity dissipated to become acceptance. Father7, like others, hoped that the SU will 'progress' towards a more positive future; some families felt that hope was all they had.

Father7: The hope that he would change and progress. The hope that in time he'll be an effective member in the world. He'll have something to do. (475)

3.3.2.2 'Loss' of family coherence: "We will be going forward happily and then...stop"

Families became further fractured, losing their sense of coherence. Within some families, relationships ended, in others, parents and siblings developed alternative life paths. Initially these changes are a response to their family member's mental health, exacerbated by being a victim of, or witnessing, violence and the physical separation of their family member entering a FMHH. Thus, families do not transition together coherently.

Some relationships ended within families. Here, Mother4 described how she maintained contact with her son indirectly, whilst her children, lost their relationship with him, maintained by the physical separation.

Mother4: It's been reassuring, she (family therapist) can tell me little bits of how well he's (SU) doing you know when he received my letter about how happy he was umm and that he, he really wants us to work together obviously, he hasn't just lost me in this he's lost his brothers as well, he's not seen them. (417)

Some parents' relationships ended, e.g. Mother4 separated from the non-biological but father figure of SU.

Mother4: We (partner) split up during the process of what was going on with <SU>. (12)

Additionally, this theme encompasses how different family members adapted, and navigated alternative pathways in response to family trauma.

Some parents found themselves unable to separate from the SU's situation e.g. constantly thinking about the SU being in a FMHH, waiting for a fluctuation in their mental health, frequently visiting. They had difficulties finding alternative meaning to their lives.

Mother6: The one big thing about mental health is that you do have a real period of stability, and therefore, no unexplained reason, the end of the world turns up, and as carers you're on this knife edge you don't want them to be unwell and you're just waiting for it to happen, because it has happened so many times before. (223)

Father7: You think oh S**t I have to do this again. How long is this going to last for? (432)

Mother11: Like I was saying even when we went to Greenwich he was still sort of with us all the time. [...] and we felt guilty being there. We had a great day, it was a lovely day but there is always a cloud over everything because we are worried about him. (102)

Other parents involved themselves in work and other aspects of family life.

Mother8: Well I'm having party for one (grandchild) tonight [...] I've 24 grandchildren. (279)

All parents perceived that their other children continued with their lives and transitioned through their own individual life patterns.

Mother1: They (other children) went on with their life. (414)

Structural family theory hypothesises that the removal of a member via an external intervention, results in the family boundary being compromised, causing subsystems to fracture, with the parent forming an alliance with the SU.

Systemic theory hypothesises that parents attempt to maintain homeostasis by remaining close to SU lives. Fractures occurring within the family results in their inability to transition through the family life cycle together. Mother9 used powerful imagery regarding the impact on her family.

Mother9: Prison wasn't the place [...] it wasn't just <SU> that was in prison, I was in prison! His siblings were in prison! (101)

3.3.2.3 Other family transitions: "I was put in intensive care"

Families needed to adjust to other challenges as a consequence of having a member with MH difficulties and violent behaviour e.g. physical injury, moving home as a result of violence, leaving work because of family responsibilities, funding private health care. These were additionally disruptive, difficult and unexpected events in family life.

Mother11 described closing the family business because of the impact her son was having on them. She prioritised her 'parental 'role and ended her role as an employee, requiring quick adjustment.

Mother11: ...things got all very difficult because he (SU) made life umm very awkward and he was ringing up threatening, it was becoming very difficult to work like that, so we had to sort of finish quite quickly. So, I haven't worked umm that would be 5 years ago in August and I haven't worked since then. (292)

Mother9 spoke of the impact of stress on her physical health, and, despite this, the necessity to support her son, given the lack of alternative support.

Mother9: I developed blood pressure ummm I was ill. I had to keep going on so that I could support him. Because even himself even <SU> the support available to him was almost nil.

Additionally, families also had to manage traditional life transitions including; death, moving house, ageing. Many were also challenged by their own MH and physical health difficulties. Some parents understood this to be a result of, or

exacerbated by, traumas they had faced as a result of SU MH, violent behaviours and challenges faced negotiating systems. Mother5 reflected on her mental health difficulties experienced (not in extract) before her mother died, concerns about ageing and consequent inability to care for her child. Traditional family patterns suggest that children eventually support their parents, here this was reversed.

Mother5: We know he will always need someone to look after him. We tell him we are getting on in years and that we would love to but we are not able, because. I get my, you know since before mum passed [...] but when she died a depression came over me in the grieving period. (261)

3.3.3 Holding The Family Together: "I've Had To Lean to Counsel My Children" This theme encompasses the roles undertaken, abilities, and efforts of families to manage relationships within the family and maintain a sense of coherence. The theme encompasses how families kept their relationships intact and stayed connected to the SU. Parents emphasised their role and their responsibilities in meeting the demands of their families' internal and external pressures.

3.3.3.1 Holding the families' relationships together: "You put on a brave face" This theme captures the ways in which families developed strategies to keep the family connected and defended from internal/external stressors, so reducing negative impacts. Families did this by 1) using their resources to support themselves, 2) parents protecting their relationships with their children and partners, hoping that their family will repair, 3) protecting from intra and extrafamilial stigma.

The wider family, partners, siblings and children were supportive of parents, providing emotional and practical help; for some the only support, available.

Mother6: So, my brother was very supportive in all of this, when you think he's married and got his family and this that and the other, but it was a help. (68)

Mother11: He's (husband) an absolute rock actually and I think, well if we didn't have each other I think it would have been desperately hard [...] I guess a lot of families may split up over things like this [...] But I think we've just supported each other and kind of got through it together really. (366)

Parents protected their children from their own pain and reassured their families that they would survive. Three families spoke of their anger towards their children for not visiting and/or forgetting their brother, but parents also 'hid' their feelings in order to protect their relationships.

Mother1: You see if I am not strong enough then the children will go down. I have to be strong for the children. (429)

Mother9: Your life is on hold. And when you see the siblings, when I see the siblings sometimes and they are doing their own thing because life goes on, sometimes you stop yourself from being angry with them because you think you're ok, that's alright then but what about <SU>? But it's not their fault, their life shouldn't be put on hold. (460)

Relationships with partners (non-biological parents) were also protected, by not discussing their son because of fear of judgement, meaning parents often felt alone within such relationships. The "family unit" protected itself by avoiding discussions about the SU with the wider family and community due to stigma, thus distancing itself.

Mother9: In fact, where you expect support sometimes you can be disappointed. My husband is an example, [...] he does not have any understanding, when it comes to the area of mental health, so I don't talk to him about it [...] it is an added burden. (521)

Mother6: I said I'm not trying to protect you (married son) I'm just protecting your family unit, because <daughter-in-law> has this melt down about it because she thinks if you say paranoid schizophrenia to her that she will instantly think someone is going to come through the door and murder her ... we don't say anything. (131)

Mother1: ...more like I didn't want the community to know about it, because most of them are not educated and also they don't know and they say different things that hurt me if I [...] because I've heard them talk about other children who have these sorts of problems you know. I had to keep it to myself. (320)

Where families perceived their family unit as fractured they expressed hope that relationships would repair.

Mother11: So

brother> doesn't have anything to do with <SU> which is really sad because they were really close. We hope in time things will mend but at the moment, that's not going to happen at the moment. (115)

3.3.3.2 Keeping the Service User within the family: "I forgive you"
As noted the relationship between the SU and family was tested in many ways.
Families did three things to sustain this relationship, 1) stayed in contact with the SU 2) made sense of the violence and forgave the SU 3) contained their feelings about the SU and associated challenges.

During the interview period, all except Mother4 were in direct contact with their child, whilst Father10 and Mother11 were asked not to visit their son because of violence towards them. However, all parents wanted to be involved in the SU lives and did so within the limitations of the FMHH, via phone-calls and visiting, although frequency varied. Factors affecting frequency of contact included the SU behaviour, symptoms, treatment and consent and willingness of families. In relation to structural family theory the family becomes hierarchically imbalanced, as the SU and the FMHH have more control over contact than parents. This is related to the SU being a consenting adult to access treatment, within the theme "challenges with systems".

Mother8: You know we speak on the phone nearly every day. (90)

Parents experienced negative emotions e.g. anxiety, sadness, feeling overwhelmed, prior, during and post-contact with the SU and some dealt frequently with physical or verbal aggression by the SU.

Mother6: You know my son is screaming at me and I now have to leave that ward after a very nasty experience in the visit, which you would think would be quite nice, but then I have to go two and a half hours on the underground. (338)

Mother8: By the time I get there my eyes are half way down my face and I'm a bit of a state, but I don't go as often as I should – I can't go up there all the time [...] it is very stressful to see my son there. (96)

Father 10: I feel washed out and deflated. (72)

Despite the negative impacts of contact and the "challenges with systems" (basic theme), parents demonstrated their resilience by maintaining contact with the SU and sustaining their parental role and identity by offering the SU advice and comfort.

Father7: ... or if he was feeling paranoid he would be able to ring up and talk about it [...] Well if its "I'm feeling paranoid I feel people are reading my thoughts they are going to attack me, so I have to attack them first".

Sometimes you've got to talk him through that – "what's your evidence? Are you sure?" What you feel is not always the case, which I think is true for all of us, but when it's after an incident and he is trying to justify himself – it's disappointing and its infuriating. (381)

Once in the FMHH, some relatives of the SU i.e. grandparents, siblings of the SU were supportive and remained in contact. Father3 described a time when some of the family spent time together; reconnecting family relationships, forming a sense of 'wholeness'.

Father3: <SU sister> she's been very good (at visiting) and we've taken <SU brother> and <SU> out the park for a couple of hours, this was before it got cold and he (SU brother) brought one of his sons [...] they're good, they're good for <SU> yeah because he's seeing people. I: What's it like for you? Father3: Its very good actually yeah. (182)

Where parents had been the victim of violence they attributed this to the SU MH, a cognitive strategy which protected their relationship with him.

Mother4: I don't want to have to fight and be strong and I don't want any of it I just want it to go away [...] It's happened now and again, and I thought, I wish I hadn't F**king survived it because it's a lot to have to deal with. To think my own son did this to me, to try and separate it, and realise he's done it because he's unwell, not because he hates me, and try and live as well. (231)

Mother4 described how she attributes her son's violence to his mental health. She spoke about this in the context of complex emotions she had to process e.g. fighting, being strong, shock, near death, wishing to die. Later this parent described using the violence-mental health rationale to persuade her family to visit him i.e. "he's not a bad person and he can't help it". Mother1 made the same attribution when trying to reassure the SU.

Mother1: I would say I have forgotten about it, you were suffering, it's not your fault you were not well. You know all these things, but he couldn't get over it, so I kept telling him that you know, that I have nothing against you. (200)

In order for families to keep connected with the SU and/or form a safe understanding of the SU violence, parents were required to hold a complex array of feelings about the SU. Mother11 described how she holds contradictory emotional positions of care, compassion, and fear of her son, and the impact on her.

Mother11: A total wreck, I think now. I suppose I was a bit of a fighter and I was never going to give up on him, because I felt that I wanted to help him, but at the same time he was dangerous. He was dangerous. I've just muddled through the last 5 years to be honest. I've felt really quite ill, and some days I just feel so tired and so worn out, I just don't feel like doing anything much. (355)

Some parents feared future violence from the SU irrespective of whether they had suffered violence previously.

Mother8: My children say to me well why don't you trust him (SU) mum? And I can only say I don't want to wake up dead. I don't want him in my house. (436)

Some parents felt guilty, worrying that they may have caused the SU to be unwell and/or in supporting the FMHH admission. This is associated with issues of responsibility in the "parental duty" theme. Mothers 4 and 5 wondered whether their sons' difficulties were caused by their genetics or parenting.

Mother4: Yeah because you think has it come from me (MH difficulties), is it to do with my family? (494)

Mother5: You (have concerns about) know the length of time that he's been in there, you know you wonder what you did that wasn't helpful, you know but apart from that I don't really worry. (105)

'Guilt' was compounded by ongoing blame from some SU towards their parents for their MH and situation. Mother11 commented on her self-blame; reinforced by the SU blaming her and her hopes for forgiveness.

Mother11: I think I need to be doing more to try and take my mind off things, but I think I kind of, I can't forgive myself for taking him (SU) to court basically, and of course when we speak to him now he kind of blames us for that. I just hope that in time he will come to understand why we did it, and that I hope that he will kind of think, "oh I can understand why they did it" and forgive us for it, at the moment I don't see that ever happening. (326)

3.3.3.3 Parental duty: "I'm his mum"

'Parental duty' describes the implicit and embraced role that parents undertake, although some interchanged 'parent' and 'carer' labels. Parents felt they were

the only "real" social contact the SU had, with a responsibility to advocate for their child and absorb the consequent stresses. They emphasised that meeting the demands of the families' external and internal challenges was their role; this belief gave them strength to persevere.

Father7: I think I am doing what I'm supposed to be doing as a dad really. (486)

Mother4: He's just my son and I'm his mum and that's all he's got; he hasn't got his dad. (258)

Mother9: I was the one that carried the brunt of it really. (101) Mother9: But I think the whole thing really rests on me. (418)

Here, parents enacted their traditionally dominant role. Parents emphasised their parental identity, perhaps an identity they felt familiar with when their responsibilities as "caregivers" were removed. In the context of felt powerlessness and lack of perceived existence by the FMHH (see "Impact of negotiating systems") their parental identity provided meaning and perceived status.

Parents took on the responsibility of 'holding' the many issues that impacted the family, including those in "negotiating systems" and "fractures within the family". Mother2 described the enormity of 'holding' these challenges whilst appreciating the fragility of her family's situation and her lack of control of it.

Mother2: I suppose holding, holding the situation together, holding <SU> together, myself, pretending things are normal, let's just carry on but they're not you know at some point umm things just become very fragile, don't they? But it's not right, it's not right, and you try and glue it back together, or hold it, and you know it's not going to happen, so you have to just let it go. (216)

3.3.4 Factors That Influence Families' Ability To Adjust: "Just Keep Going"

This theme acknowledges the strategies and resources families adopted to maintain their wellbeing when challenged by having a member in a FMHH, including; personal characteristics, behavioural and cognitive coping strategies and use of religion and social support.

Some families used avoidant coping strategies such as not thinking about their problems or the future.

Mother8: Oh no, no, no, no. I never think of the future. It never works out, no...If I thought of the future I'd never sleep! (511)

However, the majority of families talked of coping by carrying on with their lives "as normal"; this could be interpreted as an adaptive coping strategy, and/or families were attempting to reduce the likelihood of further change and maintain homeostasis or they were unsure of what adjustments to make. Father7 below described his coping strategy of routinely visiting his son, twice weekly, over the previous 14 years.

Mother2: So, you just get on with it and you kind of think, you just carry on as normal, "it's alright" and that's what you do really. (96)

Father7: What's not managing? In one sense, you have just to get on with it really. Do the visits. Not coping would be not doing the visits. (269)

Mother5 too depended on this strategy and her faith. Many families reported that faith provided strength to cope.

Mother5: Just get on with life and umm don't think about too much of the problem just get comfort from the Bible [...] Just get on with life. (220)

Families also used behavioural strategies to distract them e.g. work, solo activities, to distance themselves from their 'parental/carer role'.

Mother2: And for me its yoga once a week, its piano, its cranial therapy [...] I have designated things that are just for me and I suppose that helps. (155)

Families used friends and the community as sources of support, if they had an understanding of mental health and were non-judgmental. Families knew few people who could offer this support without fear of being stigmatised or marginalised. Mother9 spoke specifically about stigma within her culture.

Mother9: We (friend from same culture) talk at length, because when somebody is able to understand the situation, it's different. The majority, especially in our culture, in our culture it is a taboo so you have to be careful of who you talk to, you can't just talk to somebody, because they look at mental health in a different way. (511)

Many parents described personal characteristics which aided their ability to cope e.g. "stubborn" (Mother4), "fighter" (Mother11) "resilient" (Mother2). These resilient characteristics are described in the literature as "hardiness".

4.0 DISCUSSION

4.1 Overview

This study explored families' experience of the process of adjustment/change when a family member is in a forensic mental health hospital (FMHH). The findings are considered in relation to the research questions and explored in detail in the context of the FMHH literature and the conceptual frameworks outlined in the Introduction. A critical review is provided, with a discussion of the study's limitations. Implications for practice, policy and future research are presented.

4.2 Research Questions, Findings And Previous Literature

The significant strength of this research is that although some Service Users (SU) were not violent to family members and were admitted to the FMHHs via various pathways, all families provided similar descriptions of their experience.

4.2.1 In What Ways, Does Having A Family Member In A Forensic Mental Health Hospital Benefit And/Or Challenge The Family?

The various admission pathways to a FMHH resulted in different forms and lengths of service contact experienced by families. Families described the SU's pathway to admission and stay in a FMHH as complex and challenging, significantly impacting them and affecting the families-FMHH relationship.

When families described their contact with services/organisations e.g. Community Mental Health Team, prison, FMHH, they often described them as one "system" as opposed to separate service provisions. Families may have done this for two reasons; pragmatically, there were numerous services and organisations that families came in to contact with and therefore, for simplicity during the interview, referred to all services as one.

Families may have also been referring to difficulties differentiating between the abstract conceptual separation of legal and psychiatric systems, as the difference between these systems does not translate neatly into practice (Rogers & Pilgrim, 2010).

SU and families differed in the level of contact they had with the legal and psychiatric systems during their journey, however, at the time of interview all were subject to both i.e. they were in a psychiatric hospital and subject to part three of the Mental Health Act 1983. However, psychiatry is the dominant framework within FMHH, here SU are "psychiatrised" and have been deemed appropriate to be "treated" as opposed to be "criminalised", sent to prison and "punished". Both systems are state interventions aiming to control "deviance" (Rogers & Pilgrim, 2010). Although families reported that the different systems placed different demands on the family to negotiate, families also described that they challenged the family in similar ways. The challenges of most significance to families were the sense of lost control in relation to the more dominating powerful systems, the intrusions and resulting tensions between family members and "the system".

Families reported no perceived benefits of the SU being admitted to a FMHH. Feelings of relief and hope were described by families following SU admission, however these were relative to SU prior environment e.g. prison, and were short-lived as families encountered further challenges e.g. learning the visiting procedure and finding out which staff member was best to communicate with.

The findings were consistent with previous research; challenges that families experience when they have a member in a FMHH in England did not contradict international research. These challenges are: navigating and adapting to complex mental health (MH) and criminal justice systems; inadequate accessibility to information and communication with health professionals, little or no involvement or opportunity to support SU care decisions, concerns about treatment and bureaucratic hurdles (Ridley et al., 2014; Rowaert et al., 2017; Pearson & Tsang 2004; McCann et al., 1996; MacInnes & Watson 2002; Tsang et al., 2002; MacInnes et al., 2013; Ferriter & Huband, 2003; MacInnes 1999; Nordström et al., 2006).

Families reported being particularly challenged at two time points during the SU journey through the different services, when attempting to access MH treatment for the SU at the onset of their MH difficulty; and when their child was in prison

and not receiving MH treatment. Families described lacking support external to the family system i.e. service provision and needing this particularly when SU refused MH treatment.

As others have found (Ridley et al., 2014; MacInnes et al., 2013, Ferriter & Huband, 2003; Rowaert et al., 2017), the most significant challenge families reported facing was the lack of information provided across the services they came into contact with. When provided, families criticised it as unhelpful and insensitively communicated. Families expressed wanting different types of information over time, including legislation information.

These families described feeling uninvolved in SU care at the FMHH but all wanted the opportunity to collaborate with clinicians to support the SU; an issue commonly reported (Ridley et al., 2014; MacInnes et al., 2013; Rowaert et al., 2017). Families queried whether the lack of invitations to meetings was due to SU non-consent or FMHH neglecting their duty. They discussed their wishes for SU to receive psychosocial therapies and reporting their beliefs that medication is not conducive to long term change, perhaps a result of society's increased awareness of psychological therapies or their own observations.

Families reported issues of SU consent and confidentiality as barriers to the FMHH sharing information, SU accessing treatment, families' involvement in care and visiting. Although issues of confidentiality are known to negatively impact on staff-families' relationships (MacInnes & Watson 2002; McCann et al., 1996; Ridley et al 2014; Rowaert et al., 2016; Rowaert et al., 2017), these issues have not been highlighted to this extent previously. Occasionally parents used these terms out of context, perhaps because they hadn't been offered an explanation or were misinformed.

Families described facing service policy, procedural and environmental challenges when visiting the SU; these impacted on frequency and experience of families visiting (Ridley et al., 2014). FMHH literature has not reported on the extent of upset experienced by families when witnessing other SUs' distress.

Challenges negotiating systems considerably impacted on these families. The majority of these are not novel within FMHH literature.

Families in this study, like others previously, described their beliefs that the MH system 'failed' to prevent the SU offending behaviour because appropriate support was unavailable or inaccessible (Rowaert et al., 2017; Nordström et al., 2006). Families described not feeling listened to and as a result needing to "fight" when advocating for their child across services, echoing previous findings (Rowaert et al., 2017; Ridley et al., 2014). Additionally, families considered that lack of recognition by systems went beyond "not feeling listened to", they spoke of FMHH's not recognising, their value in supporting their son, the difficulties associated with having a son in a FMHH, the traumas endured or their general existence.

Families' feelings of powerlessness in relation to services, have been previously reported (Ridley et al., 2014; McCann et al.,1996; Ferriter & Huband, 2003; MacInnes & Watson, 2002). In the present study families reported two distinct areas of felt powerlessness 1) the state's intervention in 'care' and enforced separation from the SU 2) the invasion of family life.

Families described their physical separation from the SU as traumatic, and expressed feeling disconnected from the SU, perceiving they were kept at a distance by the FMHH, which some felt was intentional. In line with previous research (Ferriter & Huband, 2003; Rowaert et al., 2017), some families described feeling blamed by FMHH for the SU MH and violence.

Families stated feeling disempowered because "the system" intruded upon their life and controlled SU contact and care, length of admission, and location of FMHH. The current study's findings suggest that families interpreted their threat levels as high, due to challenges faced in negotiating systems. This pattern of appraisal, i.e. high threat and low control, is associated with adjustment difficulties in MH "carers" (Mackay & Pakenham, 2012).

Using Structural family theory, it could be hypothesised that state intervention has permeated the family's external boundary leaving the family vulnerable. Perhaps the weakened family boundary is the reason the FMHH does not recognise the family as a system, whilst families perceive the FMHH to be "intrusive".

Families in the present study recounted how they counteracted their sense of powerlessness by being persistent and resourceful in negotiating the system, although this was associated with costs e.g. physical, mental health and relationships, as reported by others (Rowaert et al., 2017; Ridley et al., 2014).

Due to families perceived systemic failures, challenges encountered and their consequent impacts, families expressed how they did not trust "the system". They felt let down by all services and expected this to continue. Families reported having "fought against" systems but wanted "collaboration with" FMHH. Such a relational shift requires the development of a trusting relationship.

4.2.2 When A Family Member Is In A Forensic Mental Health Hospital What May Change In The Family?

The process of change/adjustment within families when a member is in a FMHH is a new area of research. The extent of the findings within FMHH literature are that families may 'disintegrate' following murder within the family and imprisonment of a SU (James, 1996) and that "family relations" (not described) are burdensome for these families (MacInnes & Watson, 2002).

These families' detailed complex adjustments within the family. Families reported how they changed following the onset of the SU MH difficulty and/or the witnessing/being the victim of, violence, subsequent admission and stay in a FMHH.

Systems theory's principles of holism and circularity apply to these families. Thus, the whole family is impacted by SU deterioration in MH, violent behaviours and admission to a FMHH. Families described relational ruptures between members and ways in which feedback strategies were employed to stay connected to one another and continue as a cohesive functioning system. Importantly, irrespective of whether family violence was the factor leading to FMHH admission, families reported similar processes.

A family member developing a MH difficulty, and being admitted to a FMHH, could be described as two unexpected family transitions, compounding family stress. Families narrated their reactions to these transitions in several ways; perceiving 'loss' of the SU, relationships ending within partnerships, and with

the SU, and members undertaking divergent life patterns. Subsequently, families conveyed losing their sense of coherence as a family unit.

Parents described a feeling of 'loss' of their child during initial phases of SU distress, which continued when their MH deteriorated (Ferriter & Huband, 2003; Nordström et al., 2006). 'Loss' was expressed by families in descriptions of their child not achieving traditional life transitions e.g. marriage. Families reported feeling helpless in relation to SU distress, citing that they were unable to fulfil 'parental norms', consistent with previous findings (Nordström et al., 2006). A novel finding was the families' perception that SU 'loss' was prolonged when they did not observe positive change in their child's MH whilst receiving "treatment", although some families conveyed passively accepting that progress would never occur. Families in this study, like those reported by Livingston and colleagues (2016) described their concerns about whether SU would become lost to "the system" forever and not return to being part of "normal" family life.

Some parents, reported relationships with partners had ended, reducing their available social support network and increasing their sense of isolation. Where relationships ended with the SU families emphasised a lack of opportunity to repair relationships once the SU was in a FMHH, due to reduced physical contact and opportunities to communicate.

Families commented that within their family unit members chose alternative life patterns. All parents who had other children than the SU reported their perceptions that the SU siblings had moved on with their lives independent of the family unit; a 'typical' transition in Western cultures. These observations appeared to aggravate parents because of their perceived lack of care the siblings held for the SU, which by default increased the sense of responsibility parents had for the SU. It is considered that parents who had other children also directed frustrations at them (not SU) because they provided a relative contrast as to what the parents felt the SU had lost. In relation to structural family therapy, it could be proposed that a split in the sibling subsystem, by the removal of the SU from the family and into a FMHH, created separate subsystems, which, although difficult for the family system to tolerate, enabled the siblings to move forward with their lives.

Life for some parents was described as dependent on the life of the SU within the FMHH, they felt confused about adapting to their changed "caring role". Other parents reported having adjusted to their reduced "caring" responsibilities and created further 'meaning to their lives'; this adjustment was associated with longevity of hospital stay and number of admissions. Their role included visiting, phone-calls and attending appointments when invited, allowing them to pursue other life meanings and identities. A hypothesis from Structural family therapy explains why parents find it difficult to distance their lives from the SU, i.e. a parent-child 'alliance' (close bond across sub-systems), developed whilst the parent advocated for and protected their child prior to admission, and changing this relationship is difficult within a FMHH context because of the continued pressures on parents, e.g. parents link SUs to the external world.

Families also described having to adapt to unexpected life stressors e.g. physical injury, related with the SU MH and/or violence. Such stressors, many in quick succession with insufficient time to process, resulted in many parents disclosing the development of their own MH difficulties, or an exacerbation of distress already held. These stressors are conceptualised as "burdens" within FMHH "carer" literature (Ferriter & Huband, 2003; Ridley et al., 2014; MacInnes & Watson, 2002; Tsang et al., 2002). The FMHH literature does not report expected life transitions that these families must additionally adapt to e.g. death, compounding the stress on the family. Ageing parents in this study, as in Nordström and colleagues (2006) were concerned about SU future care, known to provoke anxiety and stress (Lefley & Hatfield, 1999).

Systems theory hypothesises that, as a consequence of internal/external stressors, families self-regulate to retain stability, by re-negotiating roles, responsibilities and rules. Families in the present study described ways they developed to maintain their sense of 'connectedness', irrespective of how fragmented they described their family.

Family members supporting one another has been evidenced by others (Ferriter & Huband, 2003). However, what hasn't been made apparent previously are the nuances as to how families described their renegotiated responsibilities, for

example, an Uncle cooked Christmas dinner for extended family, to reduce the pressure on the mother of the SU whose responsibility it would normally be. Examples such as these were interpreted as changes in role and responsibility that enabled them to function and stay connected as a family unit.

Parents described their 'parental role' as their duty; they reported their role was to manage, rectify and absorb stress within the family and protect it from external pressures. Parents reported that they identified as "parent" as opposed to "carer"; perhaps because being a "carer" did not feel applicable to their current circumstances, as it could be assumed that the SU care needs were primarily undertaken by the FMHH. Thus, their caregiving aspect of their identity had been removed by the state, whereas 'being a parent' has an emotional association and cannot be similarly disconnected. It is considered that parents developed an exaggerated "parental identity" because of the abrupt change experienced, leaving the parents confused and their responsibilities ambiguous, thus they cling to a familiar identity and status.

Parents spoke of thinking patterns and behaviours that could be described as ways of developing negative feedback strategies, such as; nurturing relationships (e.g. concealing their own distress, re-assuring others), attributing their son's violence to MH and containing complex emotions regarding the SU. Some acknowledged that this was a cost to themselves, although it could be interpreted as a way of protecting their family to reduce further fragmentation and promote homeostasis.

FMHH "carer" literature suggests attributing violence in the context of MH is adaptive for the "carer" (Nordström et al., 2006; McCann & McKeown, 1995; McCann et al. 1996). Attributing violence in this way could be considered adaptive for the family, firstly, protecting the parent-SU relationship and secondly providing parents with justification for other family members to maintain their relationship with the SU.

Previously FMHH "carer" literature listed emotions felt by families towards the SU i.e. guilt, fear, shock, confusion, anger (e.g. Ferriter & Huband, 2003). This literature did not report, as this study does, parent's description of them

requiring to hold such complex contradictory emotions e.g. fear and compassion.

Families' guilt for believing they caused and contributed to the SU MH is the most consistent finding in FMHH literature (Rowaert et al., 2017; Ferriter & Huband, 2003; Nordström et al., 2006). Families in the present study referred to their genetics, parenting and life events as possible causes for the SU development of a MH difficulty. Additionally, some parents reported their belief that others blamed them for the SU MH, which supported their self-blame. A novel finding is how families reported guilt in relation to testifying against the SU, in order that he received treatment.

Families in the present study described the blame they attributed themselves categorically and behaviourally. Attributing 'behavioural self-blame' is thought to be helpful, as opposed to 'categorical self-blame' (e.g. rape survivors: Janoff-Bulman, 1979; parents of disabled children: Affleck, Mcgrade, Allen & Mcqueeney, 1985; Tennan, Affleck & Gershman, 1996). However, in this context it is thought that parents constructing a behavioural hypothesis related to the cause of the mental health difficulty is not constructive, as their child has already developed a MH difficulty and this cannot be reversed using a different behavioural approach. Those who self-blame maybe better adjusted than those who blame others or fate; accepting self-blame means control over one's own life is perceived.

Nordström and colleagues (2006) reported on families' emotional experience related to phases of the SU journey up to admission to a FMHH. This research could be extended to include the phase 'SU extended stay in a FMHH', using this study's findings. Emotions of acceptance, sustained hope, on-going fear etc. and finding alternative roles and identities, could be included.

The parents within this study reported wanting to and attempting to maintain their relationship with the SU via phone-calls and visits, to 'keep' him connected to as a member of the family. Some family members, other than the parent visited the SU, although infrequently. Visiting is reported as an important role for families (Ridley et al., 2014) and an adaptive coping strategy (McCann &

McKeown, 1995; McCann et al.,1996). Although families within this study reported contact as beneficial, it is questionable whether it benefited all, given the heavy emotional impact families described.

Irrespective of whether aggression occurred during contact, some families in the present study described visiting as a painful experience; this affected frequency of visiting, as others have reported (McCann et al., 1996; Ridley et al., 2014), because it evoked many unprocessed and difficult emotions.

Strategic family therapy could hypothesise that 'contact' maintained unhelpful, traditional patterns of relating prior to admission, e.g. some parents continued to endure abuse from the SU, with the SU controlling interactions.

Families reported SU phone-calls as unexpected, at unusual hours, highly emotive and abusive. These increased families' sense of lost control and disruption e.g. receiving abuse at home despite the SU's hospitalisation. These challenges had recently escalated because of the FMHH' mobile phone policy, which reflects families' reports.

Structural family therapy could hypothesise that staying in contact with the SU and trying to be involved in SU care, enabled parents to maintain the family's "wholeness". It also provided a mechanism to maintain parent hierarchy e.g. parents reported the advice and support offered to their children. Parents described their frustrations at not being able to 'parent' and this could be suggested that maintaining parent-child hierarchy was difficult to achieve because of issues of consent and confidentiality; here the FMHH and SU held more power.

Parents were explicit in detailing how they protected the family from intra and extra-familial stigma by avoiding discussion regarding the SU and distancing themselves in relationships, reducing families' social networks, consistent with previous literature (Pearson & Tsang, 2004; Tsang et al., 2006; McCann et al., 1996; Ridley et al., 2014).

In summary, the change process for families is difficult and complex. Some family systems appear to fracture, but irrespective of this, families develop or fall on traditional strategies to hold the family system together, although these can come at other costs, such as parental MH.

4.2.3 What Resources Are Used By The Family When A Family Member Is In A Forensic Mental Health Hospital?

Families were interpreted as using their personal internal resources as they described their personality characteristics, knowledge/wisdom, and learnt cognitive and behavioural strategies. Families also reported using their external resources: family, friends and communities, as well as service support structures, throughout their complex journey with the SU.

Resilience characteristics of 'hope', 'acceptance', 'hardiness' and 'resourcefulness', were clearly observed in the families in the present study. 'Mastery', 'a sense of coherence' and 'self-efficacy' were less explicit. 'Hardiness', comprised of three interrelated concepts control, commitment and challenge (Kobasa, 1979), was the most apparent resilient characteristic that parents described. This is associated with better family adaption (Greef, Vansteenwegen, & Ide, 2006) and functioning (Han, Lee & Park, 2007), within families with a member with a MH difficulty.

Avoidant cognitive and behavioural coping strategies was observed to be used by families, associated with poorer adjustment in MH "carers" (Scazuka & Kuipers 1999; Mackay & Packenham, 2012). Avoidance is an emotional-coping strategy, associated with higher rates of "carer burden" than problem-focussed coping (Nafiah, 2015). It has been suggested by Östman and Hansson (2001) that families with members with a MH difficulty use problem solving-strategies when situations are amenable to change; whereas emotional-coping strategies are used in chronic and unchangeable situations; this idea fits with the FMHH context and families' perception of lack of SU progress and restraints imposed by the FMHH.

Many parents in this study were understood to be present-day-focussed, fearing the future; consistent with previous findings (Rowaert et al., 2017). In contrast,

some families in the present study had "hope" for the SU's recovery and an improvement in family relationships. Hope has been found to be an important source of strength for these families (Nordström et al., 2006). Parents held emotions of hope for SU 'recovery' that often co-existed with 'loss' of SU. Based on the current study and Nordström and colleagues (2006) findings, it is hypothesised that for families who had older sons who had been longer in psychiatric care, hope dissipated over-time, 'with the 'loss' of the SU becoming more apparent.

Families in the present study also described using hobbies as coping strategies (Rowaert et al., 2017), not only as a form of distraction i.e. emotional avoidance, but they emphasised that solo-activities enriched their self-identity, beyond that of "parent/carer".

Practising a religion was expressed as an important source of strength for these families; this has also been described by "carers" who support a person with MH difficulties, but has not been identified in this population before (e.g. Rammohan, Rao & Subbakrishna, 2002).

Families described using family and friends as support, seeking further support when this felt inadequate e.g. support groups, attending family network days (FND). Despite this, many disclosed feeling unconnected, isolated and alone because the additional service support was inadequate to support their needs. According to adjustment literature, "social support" is a coping resource and associated with better adjustment in MH "carers" (Chen & Greenberg, 2004; Lee et al., 2006; Webb et al., 1998, Mackay & Packenham, 2012).

Parents were considered resourceful in sourcing support services for themselves; some families were understood to try and re-gain control of their lives by accessing support for their wellbeing. Families reported attempting to access GPs for physical and mental health needs, secondary care psychiatric services for medication and psychological therapies and third-sector services for guidance and "carers" support groups. Most families reported having attended FND at the FMHH to feel connected to the SU, FMHH or other families. The Family Therapy (FT) Service at the FMHH had been accessed by

a few families, with many on the waiting list hoping that this would positively change their family.

Families stated their beliefs regarding support from services as poor, and, if available, was a struggle to access, inconsistent, inappropriate or untimely. Generic support offered by services was reported as not specific enough to meet their needs. Previous studies have commented on the variable helpfulness of support for families (Ridley et al., 2014; Ferriter & Huband, 2003). Parents reported that SU siblings have accessed university counselling services, which parents believed was related to SU distress. Siblings have not been recognised as needing support in this way in FMHH literature.

4.2.4 Applicability Of Conceptual Frameworks And Suggestions For Research
This research is unique in tentatively applying psychological theory to families'
experience of having a member in a FMHH

Adjustment and resilience models, like those outlined in the Introduction, can be applied to individual "carers" in a FMHH context. However, the findings from the current study and previous literature suggest that families face severe challenges, creating an inherent imbalance of "burdens" which overwhelms an individuals' ability to use their "natural" coping resources and strategies. Without sufficient, appropriate service support, families have reduced opportunity to positively adjust. These theories focus on an individual's internal constructs i.e. cognitions, personality, rather than context or interactions within systems, so arbitrarily separating family members' experience from that of an interrelated family system. These models therefore don't appear to go far enough to describe the complexity and changes that families make in order to adjust to their trauma experiences.

In contrast, the principles of systems theory, and associated family therapies, were helpful in understanding families' responses to their stressors. Further research in how these families adjust using these frameworks will support the use of family therapies offered in FMHH.

There were observed to be a lack of 'family recovery' processes (Wyder & Bland, 2014) identified within the analysis. This model is based on a relationship where the SU with a MH difficulty, within the community has fluctuating dependency on the family for care. However, families who have a member in a FMHH do not maintain a direct caregiving role. Perhaps processes of 'family recovery' are more difficult for such families because of the enforced separation and role confusion, compounded with the lack of support to aid this, more time is required by families to process change. Further exploration of 'family recovery' is required, including comparisons of experiences of families at different time-points along the SU journey.

'Hope' for the SU was the only distinguishable 'recovery-oriented caregiving' process (Wyder & Bland, 2014) in the present findings. This is understood in the context of parents' ambiguous and confusing role, as their caring responsibilities are devolved to the state.

The theoretical frameworks available to the author are not comprehensive enough to conceptualise the challenges and adjustments these families make. Families' experiences reflect characteristics of multiple traumas. As a consequence of the distress of a family member, these families can experience: violent behaviours, physical injury, destruction of the home, and emotional abuse. This impacts on the whole family, their relationships and across all life domains e.g. finances, mental health. The MH "carer" literature formalises this impact as "primary/secondary/subjective/objective burdens" or "secondary traumas" (Wyder & Bland, 2014). It is argued the term 'family trauma' is more appropriate for families with a member in a FMHH. Further trauma results from contact with dominating systems that must 'be fought' or 'submitted to', rather than opportunities to 'collaborate with' or be 'supported by'. Research conceptualising these families' experiences through a trauma lens is warranted to understand the strengths of families, resources used and further support required to adjust positively.

4.2.5 Rationale For A Lack Of Family Involvement And Support Of Families In Practice

Despite the known benefits of involving families in SU care (Ridley et al., 2014; Canning et al., 2009; MacInnes, 1999), FMHH were perceived to lack; accessibility, support of family involvement in SU care and provision for families.

A psychoanalytic theoretical approach would understand this practice as an unconscious defence, where it is too painful for the system to consciously acknowledge their lack of ability (e.g. resources, knowledge) to care for the family as well as the SU. Object Relations theory (Klein, 1952) could be used to formulate the underlying mechanisms by which the systems keep families at a distance. The FMHH system splits the anxiety and fears held about its inadequacy and project this on to the family. The family system is denigrated and blamed, whilst the FMHH system is idealised; and the concept that "we understand care better than families" is expressed. A pattern of hostile relationships is developed and maintained, exacerbating the chasm and felt hopelessness between systems.

Secondly, the FMHH could be holding historic, but persistent narratives of blaming families for causing, or sustaining the family-members MH difficulties, or contributing to relapse e.g. "expressed emotion" (Butzlaff & Hooley, 1998).

Thirdly, FMHH are impacted by economic, cultural, and political macro-systems and are in a vulnerable position. They are threatened by; heavy scrutiny because of their "public protection" role, resource cuts as a 'high-cost and low-volume' service, the stigma and morality attached to caring for the "mad" and "bad" and an increasingly litigious society. Those attempting to implement policy and advocate for family involvement in SU care and family support within a FMHH context have a difficult task as more powerful systems restrict their practice.

4.3 Critical Review

4.3.1 Quality Assurance

The present study used Nowell et al.'s (2017) guided steps to ensure a trustworthy analysis outlined in the Methodology chapter (section 2.3). The study used several techniques to address credibility. Thick descriptions of

themes are provided (Appendix Q), so that findings can be transferred and generalised to other FMHH settings. The author reviewed the findings, in the light of previous literature, and they were consistent. The research achieves dependability as a documented trail of the research process, that can be audited, and is available (e.g. Appendix M/P). The analysis is believed to be credible, transferable, dependable and thus confirmable (Guba & Lincoln, 1989). True validity within qualitative research concerns the extent to which research is useful and communicates to the reader something of importance (Yardley, 2007). This research provided a platform for families who have a member in a FMHH, to share their experience. The author believes this research is important, with useful implications.

4.3.1.1 Reflexivity

The research journal captured the author's personal reflections regarding the research process to support the latent part of the analysis and to reduce research bias. Having approached the research from a critical realist position the findings do not offer a general truth about families' experience when a member is in a FMHH, these interpretations and conclusions are one possible perspective influenced by the author's contexts of "carer" and trainee clinical psychologist with experience of working within FMHH.

As a MH "carer", I want to empower other "carers" and improve services for families. I became aware that this view was not a priority held by all clinicians, with little support at research sites. I felt a strong personal connection to families describing their commitment to their family and angry about the injustices they suffered. Journaling enabled me to disentangle personal and interviewees' feelings whilst interpreting data.

I was aware of the power imbalance, and potential negative assumptions participants held about me as a trainee psychologist, including being part of "the system". I tried to provide a sensitive experience within a research context e.g. by showing empathy, although I felt that this must be of little comfort. During interviews, I noticed that I prevented interviewees criticising other professions. I reflected my sensitivity around psychology's professional position within a FMHH, i.e. supporting cohesion within teams, and my fear was that particular professions would be perceived as 'poor' in the analysis.

Interviewees reflected that they lacked opportunities to talk about their experience and that this was helpful in relieving pain. This re-enforced the 'message' from interviews, that families need to be better, appropriately supported.

4.3.2 Methodological Strengths

Methodological strengths of the present study include a diverse sample representing different family compositions, cultural and religious backgrounds. It is usually the mother's voice found in "caring" literature; here, fathers were found to be equally involved with SU life, and in need of support.

A Critical Realist epistemological stance was used consistently throughout the research, maintained through reflexive journal and supervisory discussions.

Conclusions drawn are tentative, appropriate for some of the novel findings.

4.3.3 Ethical And Methodological Considerations

4.3.3.1 Thematic Analysis

Thematic analysis (TA) was used to generate an understanding of patterns across interviews rather than individual insights. Valuable aspects of individuals' experiences, that could provide further understanding regarding families' adjustment, may have been missed. While it may be useful to consider alternative forms of analysis, it was felt that TA was most appropriate in answering the research questions.

4.3.3.2 Data collection and social desirability

Some families tried to portray their family, especially the SU, in a socially desirable way. This was understood as a way of protecting their family from societal stigma about MH. Although the study was explained and questions asked sensitively, such inherent stigma is difficult to reduce. Social desirability may have prevented families describing in detail the complexities of relationships and changes within the family.

4.3.3.3 Recruitment

A sub-set of families who met criteria of 'having a relationship with the SU and FMHH' were recruited. Those families without this relationship are not represented in published literature, thus there is no understanding of such families' experiences. Secondly, SU consent was required, restricting the

number of families that participated (57%). Only parents were recruited, and although parents did discuss the experience of siblings, this maybe poorly represented.

4.3.3.4 NHS ethics

Gaining ethical approval was a complex and challenging process, requiring a year of sustained effort. Ethics committees were unfamiliar with qualitative research, context and population; misunderstandings and inappropriate suggestions occurred, and compromises were difficult. The Ethics Committee found it difficult to reconcile transparency with the SU and the family's voice, so re-affirming families' powerlessness in addressing change in "the system".

4.3.3.5 Cultural differences

Some participants referenced their culture in relation to their experience, but there was insufficient data for appropriate analysis. Black Minority and Ethnic (BME) populations in FMHH are over-represented (e.g. Coid, Kahtan, Gault, & Jarman, 2000) and the literature does not report differences of ethnicity, culture or religion in families' experience in this context. Cultural differences impact the way in which family members relate to one another, including the extent to which violence is tolerated, a contributing factor influencing whether families access MH services (James, 1996). Exploring cultural perspectives could greatly improve service provision for families and SU care.

4.4 Implications And Recommendations

The current study increases the awareness that families with a member with MH difficulty and who display offending behaviour are a vulnerable population whose voices are oppressed by structural forces around them. These families' lives have been constructed by the social, political, economic and cultural contexts within which they live. Bronfenbrenner's Social Ecological Model (1979) is used here as one way for health-care professionals, including clinical psychologists, to frame how these families, at different levels of context from the micro to the macro, can be best supported. In particular, clinical psychologists will have developed the relevant assessment and formulation skills, through their training, to guide individual and family interventions, and developed the

skills to work within organisations to promote change and advise policy-makers and commissioners regarding policy and service delivery.

4.4.1 Policy And Structural Change

FMHH sit in a unique position between health and the CJS, thus SU and their families' come in to contact with both these systems, and others e.g. third-sector. The challenges and therefore the changes within the relationship between, families, the CJS and the health system need to be addressed in their contexts.

These contexts must be actively engaged with to promote change. At present, there is no governmental cross-sector health and CJS policy regarding families' support. Policy must bridge these systems for families to experience positive contact and reduce the traumas that families report when in contact with these systems. Clinical psychologists within FMHH are in a privileged position to actively engage with the policy literature, provide further evidence for the change needed and lobby political structures to advocate for such change.

For example, families in this study reported needing emotional support, advice and information about MH and the law, in order to advocate for their son and gain support for themselves; a service they understood to be non-existent. They thought this support service should run concurrently with the SU journey. Families described requiring this support particularly during vulnerable periods e.g. when the SU has not consented to treatment prior to FMHH admittance, or whilst in prison custody.

4.4.1.1 Early intervention in the community

FMHH are often the last "treatment" option for those who offend and have MH difficulties. In order to prevent SU needing to access FMHH, it is paramount that MH services are accessible when a person becomes initially distressed, to reduce further deterioration in their MH and the likelihood of offending behaviours and admittance to hospital/prison/FMHH. Families' concerns regarding the SUs distress need to be acknowledged and considered thoughtfully by services, especially when reporting SU risk.

Improving access to MH services, requires more than secondary MH services

operating alone, but also an increased awareness of how distress is expressed and how MH services are accessed, by the police, education, primary health care, third-sector and legal services. MH stigma is one of the greatest barriers to seeking help; those disproportionately deterred are those who are of a black/ethnic minority, young and male (Clement et al., 2014), these populations are those over-represented in FMHH (Rutherford & Duggan, 2007). To reduce this association, more is required to reduce MH stigma within society.

4.4.1.1.1 Families and the third-sector

As reported by the families in this study, the CJS and health system do not provide the service that families need along their journey with the SU. Families therefore turn to the third sector for support. However, this study highlighted that no independent third-sector support for families with a member in a FMHH exists. 'Family Lives' is the most relevant third-sector organisation providing the 'National Offenders' Families Helpline'. Families in the present study, were not aware of such support and perhaps would not identify with it because of the vocabulary it uses e.g. "offender". Clinical psychologists have the skill set to engage and consult with third-sector organisations and to address issues such as terminology that create barriers to families' accessing support.

4.4.1.2 Prevention of acute distress

There is considerable evidence that mental health is shaped to a great extent by social, economic and environmental factors, as a result mental health difficulties are not equally distributed across the population in relation to gender, age, ethnicity, income, education, or geographic area of residence (WHO, 2014). Those who are socially disadvantaged are at increased risk of developing MH difficulties. In order to reduce such inequalities, clinical psychologists have a role in increasing awareness of the determinants that determine these inequalities through research, and within FMHH families and community actively lobbying the government across sectors of health, CJS, social care, housing, environment etc. to address the social determinants over the life-course that increase the likelihood of developing a MH difficulty (WHO, 2014).

4.4.1.3 FMHH organisational change

FMHH are required to implement a "carer" engagement and involvement strategy (NHS England, 2018). Current practice does not meet guidelines; this was apparent to families who had recently had their son admitted to a FMHH. The right to respect one's private and family life (Article 8 of the European Convention of Human Rights: Council of Europe, 1950) is crucial here, and FMHH must provide the resources and support for families to maintain and develop family relationships. To ensure SU and family rights are adhered to, FMHH could adopt an organisational framework centred around human rights, as adopted by the State Hospital in Scotland, where a positive more inclusive culture shift has occurred (Scottish Human Rights Commission, 2009).

4.4.2 Practice Considerations

4.4.2.1 Development of trust between family and FMHH

During the journey the family takes with the SU, an oppositional image of services is developed. Once the SU is admitted to a FMHH, families' beliefs constructed on their prior experience of services become generalised to FMHHs. FMHH need to address ways to promote trust and foster positive relationships with families, preferably before the SU is transferred from a prior service. FMHH need to therefore demonstrate inclusiveness, respect, thoughtfulness, compassion and sensitivity, towards families.

FMHH must recognise that SUs are part of a family, appreciate the value of families in contributing to SU care, and that they too have experienced trauma, including significant changes in their families' lives.

To achieve this FMHH staff need to be made more aware of families' collective experience. Clinical psychologists with colleagues and families could develop training that emphasises systemic and contextual social factors that have an impact on the SU recovery. Training that challenges the dominant and outdated narrative that pervades psychiatric institutions, i.e. that families cause and maintain SU distress is required, to reduce the distress felt and reported by families.

Additionally, this training needs to describe the experience of families including the challenges they have faced and those that persist when the family member is in a FMHH. It must also address the strengths and resilience that families have displayed during their experience, to reduce the limiting and culturally dominant narrative that these families are "burdened" and "in need".

The use of "carers" in the co-facilitation of training is understood to have benefits for those being trained; including the ability to challenge assumptions, so bridging the gap between theory and real experiences. Hearing such experience directly can have a powerful impact (Carer's Matter, 2012). Training provided for FMHH staff could be co-facilitated with families, enabling them to express the on-going challenges and collaborate in problem- solving, with both parties appreciating each others' value.

Clinical/forensic psychologists could support teams in maintaining their awareness of the SU family and their relationship with their family/friends, in their day-to-day work, using their consultation skills and systemic techniques.

4.4.2.2 Family involvement with SU care

Where it is appropriate for families to be involved in the care of the SU, FMHH should enable and facilitate support for families to collaborate with the FMHH and SU. Families in this study, were already significantly involved in the life of the SU i.e. via phone calls and visits, but felt this was un-recognised by the FMHH. FMHH could formally recognise such support.

The training outlined above could help overcome some challenges encountered by families in relation to being invited to SU care planning meetings in a timely way, and, their views considered if not in attendance. This may also require edits or additions to the CPA documentation and/or supporting the implementation of the policy around inviting family to these meetings.

Furthermore, providing a reflective space for FMHH and families to consider the quality and the interactions during contact with the SU would be helpful, especially when contact is distressing, to reduce the maintenance of unhelpful relational patterns between SU- family. Clinical psychologists could help facilitate these conversations using systemic techniques. FMHH awareness would be increased and collaborative ideas could be implemented to reduce these patterns and support the family and SU.

4.4.2.3 Support for families

Families require further support from FMHH; Clinical Psychologists have a role to support the basic support that families said they require e.g. staff to enquire how they are when visiting, and the more advanced one-to-one psychological therapy.

The role of the Clinical psychologist needs to be promoted within FMHH; families in this study reported that they did not know of or had ever spoken to the SU clinical/forensic psychologist on a one-to-one basis. Psychologists have a role to play in improving families' understanding of their role in the care of the SU and the extent to which they can support families, (this will be dependent on service restrictions).

4.4.2.3.1 General support and communication

Families in this study reported that they were not asked by staff, how they were, when visiting the FMHH. It should be a given that FMHH staff ask visiting family members how they are, helping families to feel cared for. Moreover, families need to be forewarned of the potential distress experienced when visiting a FMHH, with staff prepared to listen to their distress if necessary.

The form and content of the way in which families are spoken to by FMHH staff needs to be addressed. In relation to the frequency (e.g. only at meetings with clinical team, or when the SU has a "problem" e.g. secluded, absconded, physical health issue), language (e.g. technical, abbreviations) and mode (i.e. letter, phone call, home visit, hospital visit, CPA meetings). Across the organisation the content of any message being communicated requires sensitivity and should be pre-empted by consideration of what support may be required by the family when a difficult message is communicated, and not assumed that they have support available to them outside of the FMHH context.

To reduce the harm that unhelpful communication can cause, training for staff in relation to their communication skills with family members needs to be prioritised.

4.4.2.3.2 Information sharing and psychoeducation

Families' reported a lack of information sharing about the wellbeing of their family member, their care plan/pathway, the Mental Health Act 1983, diagnostic

label(s) and helpful strategies to manage their relative's behaviour, was a significant and distressing challenge that they experienced.

Consent and confidentiality are two legal constructs that define what information about the SU, FMHH are allowed to share with the family/others. Decisions around confidentiality are made by the SU (unless deemed to lack capacity), this decision is often thought (by SU and staff alike) as absolute, i.e. information can or cannot be shared with family members, and stable i.e. doesn't fluctuate over time. The MDT are placed to support the SU in making decisions around the nuances of information that can be shared, for example, SU may want to share with their family their section given under the Mental Health Act 1983, but not want to disclose their diagnostic label.

Whether SU give consent to sharing of information with their families or not, the FMHH could support families in accessing information that enables them to make sense of why information is restricted. Workshops developed for families regarding "consent, confidentiality and the law", could promote a better understanding of information sharing, and perhaps reduce their frustration, which might otherwise be directed towards staff. Likewise, staff should be made aware of individual differences around confidentiality and training in this area should be prioritised.

Additionally, FMHH could provide psychoeducational groups for families so giving them better understanding of MH and the Mental Health Act, so that they feel better equipped in supporting their child. Families' could perhaps access this information whether they are aware of the diagnostic labels given to the SU or not, as many of the strategies used to prevent an escalation or manage behaviour that challenges, can be generalised across diagnostic labels, e.g. communication strategies. A three-session pilot psychoeducation programme developed by psychologists for families with a member in a low secure service (Nagi & Davies, 2015), has been shown to be accessible and have positive outcomes e.g. increased understanding of links between MH and offending behaviour.

4.4.2.3.3 Family Therapy

A family therapy (FT) service is not a common provision within FMHH (Davies et al., 2014). Family intervention is recommended in clinical guidelines for SU with "psychosis" (NICE, 2014), thus it should be available to these families. Although, further evidence is required, it could be tentatively suggested from the present findings that a FT service is a necessity in a FMHH, so that all families have the opportunity for support in adjusting and processing traumas. Those trained in systemic practice, would be best suited to facilitate this intervention. 4.4.2.3.4 Individual support

Some family members wanted their pain to be heard and processed in individual therapeutic spaces. Clinical psychologists within FMHH are skilled to provide this intervention, however, currently these services are not commissioned as part of a FMHH service. Clinical psychologists could therefore liaise, train and consult with general mental health services, to support them in providing a service that meets these families' needs. Additionally, they could advocate and develop a business plan as to why they, within the FMHH, are best placed to provide this service.

Families may benefit from interventions from a trauma/social inequalities informed approach. This would acknowledge the level of distress experienced by families and help enhance awareness of their contexts and inequalities that exist. This may in part reduce the perceived blame that families feel in relation to causing/maintaining MH difficulties. It may also have benefits in reducing the sense of isolation that many families experience.

Systemic techniques used in individual therapy may support families' awareness of their social context and support change in unhelpful relational and communication patterns. Narrative therapies would be of use to support families developing alternative narratives to that of "carer" or "parent of a child with a MH difficulty (and is violent)", which could encourage 'family recovery' (Wyder & Bland, 2014), in relation to the concepts of identity, meaningfulness and empowerment.

4.4.2.3.5 Group support

Families said they wanted mutually-supportive spaces to enable them to connect with other families, with similar needs. Clinical psychologists and their

colleagues, could facilitate reflective and supportive spaces, that could promote problem-solving around challenges and/or emotional containment for distressed relatives and friends. Outcomes of "carer" support groups are positive and appear to benefit "carers" (McCann, 1993; Ridley et al., 2014).

4.4.2.3.6 Care Assessments

Few families referenced the Care Act 2014, and statutory Carer's Assessments, suggesting that families were unaware of these, or they lacked relevance, so echoing findings that the Act "made little or no difference to carers in England" (Carers Trust, 2016). Such barriers to support implementation should be explored further and overcome, in order that families can access appropriate benefits. Clinical psychologists should be aware of the rights of the "carer" and support the MDT in adhering to this legislation.

4.4.3 Research

Research concerning family members' experience of having a family member in a FMHH is limited; more is warranted. Ideas of how future research could explore families' experience applying the conceptual frameworks used in this study are provided in section 4.2.4.

A longitudinal mixed-methods design across FMHH, could be used to provide further evidence of families' experience, and explore whether these, and their needs change across time and service. Service provision could then be better matched to families' needs. A wider range of family members', e.g. siblings', perspectives, and including those of female SU, should be explored to enrich understanding.

Families perceived that staff held negative beliefs about them. Research concerning FMHH staff' attitudes and beliefs about families has been conducted in Sweden; staff generally held negative beliefs about the family e.g. "most families get in the way of patient's care" (Horberg, Benzein, Erlingsson & Syren, 2015). Further research that explores whether specific interventions designed to change staff attitudes and be helpful in improving family-FMHH relationship, is required.

Importantly, FMHH need to evaluate and publish their practice in relation to the

services they provide for families e.g. family therapy, family network days, involvement in SU care meetings, to evidence the benefits in SU and family recovery and their adjustment. Clinical psychologists within the FMHH are best placed to initiate and motivate practice-based-evidence research, having been trained in a range of research methods. Developing practice-based evidence within FMHH to best support families, as opposed to evidence- based practice may have a more far reaching impact, due to its applicability (Harper, Ken & Robinson, 2012). This research could have wider implications for society, i.e., if families who have a member in a FMHH are better supported, a less distressed population will result, and this is likely to have a positive economic impact.

4.5 Conclusion

This is the first study to explore families' processes of adjustment when a family member is in a FMHH and provides initial understanding of these, with direct practice implications and suggestions for future research.

Fewer people would be admitted to FMHH if earlier prevention was available to distressed families. Families need consistent support from services from the onset of the SU distress and throughout their complex journey.

Should a person be admitted to a FMHH, the FMHH need to recognise that SUs are family members, irrespective of the SU's perception.

The family system becomes fragmented, when a member has a MH difficulty, is violent and admitted to a FMHH. Families are resilient and resourceful in adapting to trauma, to remain a functioning, inter-connected system.

Sometimes these adjustments have a detrimental impact on families. These families need to be better supported.

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6.0 APPENDICIES

Appendix A Literature Review Search Criteria

Date conducted June/July 2017

Key Term search in Abstract:

famil* OR carer OR caregiver* OR relative

AND (forensic OR crim* OR offender)

AND (mental* OR psych*)

Databases searched:

EBSCO: PsychInfo, Academic Search Complete, CINHAL Plus= 4071 abstraction when duplicates were removed

Science Direct= 470 when duplicates were removed

Scopus= 3264 when duplicates were removed

(Limits applied: English language, 1905-July 2017.)

Inclusion criteria

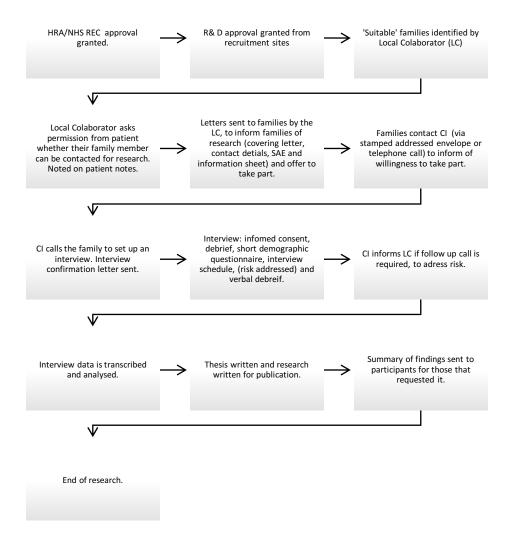
- 1) The review is concerned with the experiences of families when an adult family member is in a forensic mental health hospital and therefore the presence of these factors should be a central feature of the article.
- 2) The research should focus on the voice of the family or attempts to gain the perspective of the families' experience.
- 3) Published and unpublished work including dissertations and any use of any methodology. Reviews including any systematic or meta-analysis, to cross reference with current review.

Exclusion criteria

- 1) Children, juvenile, adolescent or youth offending.
- 2) If focus of the research is on prison, outpatient or community populations.
- 3) Primarily an evaluation of targeted family intervention.
- 4) Surveys regarding the provision of family/carer support at FMHH
- 5) Research regarding the beliefs of staff at FMHH or families regarding families and family intervention.

Bidirectional citation searching (checking references and citations) was used on the final 15 articles and appropriateness for inclusion was based on: title i.e. forensic/offender AND mental health AND family/carer/caregiver. However, no further appropriate literature was discovered.

Appendix B Research Protocol



Appendix C

Original Individual Schedule

INTERVIEW SCHEDULE: Families' experiences of having a member of their family in a forensic mental health hospital

- 1. Who is in your family?
- 2. Has the family always been 'made-up' in this way?
- 3. I understand you keep in contact with (name), how do you keep in contact with them How frequent is this contact?
- 4. Has your contact with (name) always been this way? If it has changed, how has it changed and why do you think this is?
- 5. Why do you feel it is important you have this contact?
- 6. Do you keep in contact with anyone at the hospital?
- 7. With who?
- 8. How do you do that?
- 9. Why do you feel it is important to keep this kind of contact?
- 10. Are you involved in the care of (name) at the moment? How? Do you feel it's important to be involved in (name) care? Why? What is this involvement like?
- 11. Have you or your family received support or signposting information from the hospital? What was it?
- 12. When your (name) went to (name of institution) what changed in the family?

Prompts:

How did this affect you? How did you feel when this happened? What did you think when this happened? Did your way of life change? In what way?

How did this effect other members of the family? Who did it impact most? In what way did they change?

Did the family relationships change? In what way? Did the relationships change in the family? How so? Why do you think they changed in this way?

13. Was there anything challenging about (name) going into hospital? Prompts:

Of these challenges, which were the most, challenging to you as a family? Which were the most challenging to you, personally? What about other members of the family?

Can you think of any other challenges that you had to cope with as a family during this time?

14. Was there anything that became easier when (name) went in to hospital? Prompts:

What became easier for you?
Why did it become easier?
What did this enable you to do, if anything?

Did the family notice that these things became easier?

15. As a family how did you 'keep going'?

Prompts:

What helped you to cope day by day?

What do you think helped other family members to cope?

16. Looking back from the time (name) went to (name of institution) how do you think you have adjusted as a family?

Prompts:

What did you need to do as a family to help you adjust?

What help did you need from others to do this?

17. Looking forward, what do you think will happen as a family?

Prompts:

What do you hope will happen?

Is there anything that particularly concerns you?

What do you think your family might need support with?

Appendix D Second Draft OF Interview Schedule

INTERVIEW SCHEDULE Adapted post - first interview: Families' experiences of having a member of their family in a forensic mental health hospital

Changes are italicised

- 1. Who is in your family?
- 2. Has the family always been 'made-up' in this way?

Additional Question: How long has your family member been at the FMHH? Were they involved with services before? Is your experience with the hospitals/services different?

- 3. I understand you keep in contact with (name), how do you keep in contact with them? How frequent is this contact?
- 4. Has your contact with (name) always been this way? If it has changed, how has it changed and why do you think this is?
- 5. Why do you feel it is important you have this contact?
- 6. Do you keep in contact with anyone at the hospital?
- 7. Who with?
- 8. How do you do that?
- 9. Why do you feel it is important to keep this kind of contact?
- 10. Are you involved in the care of (name) at the moment? How? Do you feel it's important to be involved in (name) care? Why? What is this involvement like?

Changed question 10 to: Do you attend any meetings with the hospital? What's your experience of these? Do you feel involved in your family members care?

- 11. Have you or your family received support or signposting information from the hospital? What was it?
- 12. When your (name) went to (name of institution) what changed in the family?

Prompts:

How did this affect you? How did you feel when this happened? What did you think when this happened? Did your way of life change? In what way?

How did this effect other members of the family? Who did it impact most? In what way did they change?

Did the family relationships change? In what way? Did the relationships change in the family? How so? Why do you think they changed in this way?

13. Was there anything challenging about (name) going into hospital? Changed question 13 to: Was there anything difficult for you or your family when family member went in to hospital?

Prompts:

Of these challenges, which were the most, challenging to you as a family? Which were the most challenging to you, personally? What about other members of the family?

Can you think of any other challenges that you had to cope with as a family during this time?

14. Was there anything that became easier when (name) went in to hospital?

Prompts:

What became easier for you?
Why did it become easier?
What did this enable you to do, if anything?
Did the family notice that these things became easier?

Changed question 14 to: How did you feel when family member went into hospital? Was there anything helpful for family member going into hospital?

15. As a family how did you 'keep going'?

Changed question 15 to: How did you and your family look after yourself and each other?

Prompts:

What helped you to cope day by day?
What do you think helped other family members to cope?

16. Looking back from the time (name) went to (name of institution) how do you think you have adjusted as a family?

Removed question- P1 didn't understand concept of adjustment in this question

Prompts:

What did you need to do as a family to help you adjust? What help did you need from others to do this?

17. Looking forward, what do you think will happen as a family?

Prompts:

What do you hope will happen?
Is there anything that particularly concerns you?
What do you think your family might need support with?

Changed question 17 to: What did your family need support with when your family member entered the FMHH? Currently, do you need support now? What support do you think you might need in the future?

Appendix E

Covering Letter To Introduce Research

<Address of potential participant>

Unit/Department name

Address line 1

Address line 2

Town

Postcode

Tel: XXX

Web:

Date

Dear <name of potential participant>,

I am writing to you on behalf of a Trainee Clinical Psychologist; Sarah Williams, as she is carrying out some research that I thought you may be interested in taking part in. Her research is about families' experience when they have a family member in a forensic mental health hospital.

The research involves having an interview with Sarah, at the hospital. The interviews usually last up to an hour. During this time, she will talk you through the research in more detail and will ask for your consent to take part in the research. Sarah will ask you to fill in a short questionnaire and then ask you a number of questions about your experiences as a family, since the time your family member went into hospital. I have enclosed more information about the project if you wish to read it, please do not hesitate in contacting me or Sarah if you have any questions.

If you would like to be involved in this research, please call Sarah on<mobile number>, <email address> or fill out the attached form with your contact details and post it back in the stamped addressed envelope. This research is optional and will not affect the care you or your family member receives from any NHS services.

Yours sincerely,

<Name and title of Local Collaborator>

Enclosed: Information sheet, Reply slip, Stamped addressed envelope

Appendix F

Information Sheet

PARTICIPANT INFORMATION SHEET: Families' experiences of having a member of their family in a forensic mental health hospital

Before you decide whether to take part Sarah, (the person who is doing the research), would like you to understand why this research is being done and what it would involve for you, if you decided to take part.

Why are we doing this study and why are we asking you to take part?

This research project aims to gather information about families' experiences of having a member of their family in a forensic mental health setting. It is understood that you have a family member in a forensic hospital.

Do I have to take part?

No, you don't have to take part. It's up to you to decide whether or not to participate in this research. Your usual interaction with the hospital will not be affected by whether you choose to take part and the care that your family member receives in hospital will not change as a result of your participation in this project.

If you do decide to take part, you will be asked to sign a consent form. Even after signing this form you do not have to answer any questions you do not wish to answer. If you feel uncomfortable in the interview you may pause or leave the interview at any time without having to give a reason. You can ask for your information to be withdrawn from this project at any point in the four weeks after the interview. You will not be asked why you want your information to be withdrawn and it will be destroyed it immediately.

What will happen to me if I take part?

If you would like to take part, please let Sarah know. You can do this by phoning her on <mobile number> or filling out the contact details from (enclosed) and send it using the stamped addressed envelope. Sarah will then contact you to arrange a time and date for the interview. The interviews will be held at the hospital where your family member is currently.

Sarah will ask you some questions about your experiences as a family whilst your family member has been in a forensic hospital. She will not ask about the details of your family member's criminal behaviour or offences before they went in to hospital, unless you choose to tell her.

Interview's usually take up to an hour (maximum 1 hour and forty-five minutes). Sarah will be able to interview up to two members of your family; however, these interviews will be held with only one person at a time. Sarah will not be allowed to interview anyone under the age of 18. The interviews will be audio - recorded and then transcribed (written out).

Will I benefit from taking part?

Research participants often find that speaking about their experiences can be helpful. This research seeks to understand families' experiences when a family member is in a forensic mental health hospital; by doing this research Sarah hopes that further research will follow which will benefit other families' in similar situations in the future.

If you are having to make a special trip to the hospital to do the interview, we will be able to pay your travel expenses (that do not exceed £15) i.e. if you were to have another meeting at the hospital on the same day, we would not be able to refund you. Please bring a receipt of your travel.

What will happen to the results of this study?

The results of this study may be submitted for publication in academic journals and presented at conferences. The results of this study will be written up as Sarah's thesis for her doctorate course in clinical psychology.

Will I be contacted after the study has ended?

You will not be contacted once the study has ended, unless you request that a summary of the findings be sent to you once the project has ended – if you would like this please tick the appropriate box on the consent form. You are welcome to contact Sarah after the interview if you have any queries about this study whilst the project is running.

Are there any risks involved?

Discussing your experiences is hopefully a helpful process, but it can also be difficult, or upsetting. At the start of the interview, you will be given a list of support services that you can use for further support if you wish. If you become upset during the interview, we will pause or stop the interview and only carry on if/when you are ready.

Who will know I am taking part in this research?

No one will know you are taking part other than Sarah and the hospital team that cares for your family member in hospital. It is your decision whether you choose to tell anybody else. Sarah will only tell the hospital team that you are taking part in the study; she will not share the information you give her. However, if Sarah is significantly concerned about a risk or danger to yourself or others, the hospital team will be requested to call you and encourage you to speak with your GP, the police or any other services you are involved with who support you. Sarah will always attempt to discuss this with you before she speaks to <Local Collaborator/Clinical team> and requests for you to be contacted.

Your family member in hospital has agreed that it is ok to contact you about this research, but they will not be told of anything you say in the interview.

When the research is written you and your family will not be identifiable in anyway, this means your personal information will be disguised.

Where and how long will my information be kept?

Your personal information (your name and contact details) will be kept separate from any other information and kept on password-protected and encrypted file and computer. Only Sarah will have access to this. Your personal contact information i.e. name, phone number, address, will be deleted once the interview has been conducted, unless you request a summary of the outcome of this research; if this is so, then your contact details will be kept up until this point (approximately August 2018) and then will be deleted.

The transcripts from what you say in the interview will only be identifiable by a unique

participant identification number. This will be kept on a password-protected and

encrypted file and computer, which will be kept in a secured place. This information

will be kept for no longer than 3 years.

The audio recordings and any other information that you give Sarah will be deleted

in (approximately) August 2018.

What if there is a problem or something goes wrong?

If you have any concerns about any aspect of the way that you have been

approached or treated by Sarah or the hospital team in connection with this research

project, you have the right to speak to the Patient Advice and Liaison Service

<contact info> run by the National Health Service (NHS) or a member of staff at

University of East London. Please ask Sarah or <Local Collaborator/Clinical Team

member> if you would like more information about this.

Who is organising the study?

This study is funded by the NHS as part of a Clinical Psychology Doctorate thesis

being undertaken by Sarah Williams (Trainee Clinical Psychologist and Researcher)

who attends The University of East London and who is supervised by Dr Rachel

Smith (Clinical Psychologist and Researcher).

Who has approved this study?

This study has received ethical approval from the NHS Research Ethics Committee.

What should I do if I want more information or want to take part?

If you want more information or you are interested in taking part, please contact

Sarah.

Mobile:

Email:

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Appendix G Contact Details Form

Contact details of person 1:
Name
I like to be called
I am the (e.g. father, sister) of a patient.
Telephone Number
Is it ok to leave an answerphone message? Yes / No (please circle)
Is it ok to send you a text message? Yes / No (please circle)
It is best to phone me in the (please circle)
morning (8am-12pm)
afternoon (12pm-5pm)
• evening (5pm- 8pm)
Address:
Post Code:

Contact details of person 2:
Name
I like to be called
I am the (e.g. father, sister) of a patient.
Telephone Number
Is it ok to leave an answerphone message? Yes / No (please circle)
Is it ok to send you a text message? Yes / No (please circle)
It is best to phone me in the (please circle)
morning (8am-12pm)
afternoon (12pm-5pm)
evening (5pm- 8pm)
Address:
Post Code:

Appendix H **Confirmation Letter**

Trainee Clinical Psychologist

Yours sincerely,

Sarah Williams

Unit/Department name Address line 1 Address line 2 Address line 3 Town Postcode
Tel: XXX
Web:
Date
<dear full="" name="">,</dear>
Thank you for agreeing to take part in the research project that I am doing about
family members' experience when their family member is in a forensic mental
health hospital.
I can confirm that we will meet on:
Date:
Time:
With: Sarah Williams
Where: X room, X hospital address
<instructions for="" getting="" if="" necessary.="" there=""></instructions>
Our discussion will last up to 1hour and 45minutes and we will have comfort
breaks if needed throughout. I have enclosed information regarding the study.
Please remember if you would like your travel expenses paid for on the day
(maximum £15), please bring a receipt of this.
If you are unable to come for any reason or no longer wish to take part, please call or email me to rearrange our meeting. I look forward to meeting you.
Value alianamah

Enclosed: Information sheet, Consent form, Map and instructions if required

Appendix I Participant Consent

CONSENT TO PARTCIPATE: Families' experiences of having a member of their family in a forensic mental health hospital

Please tick the appropriate box

Please tick the appropriate box		
	Yes	No
I have read the information sheet and have been given a copy.		
The nature and purpose of the research has been explained to me and I have had the opportunity to talk about it in detail.		
I understand the reason for the research and the procedures I will be involved in.		
I understand the data will remain anonymous unless the interviewer is concerned about the immediate risk of harm to others or myself, in which case they will inform (Local Collaborator)		
I understand that only the interviewer, supervisor and reviewer of academic research would have access to what was said in the interview and other questionnaire data, but not my personal information.		
It has been explained to me what will happen to my data once the study has been completed.		
I have been given a sheet with information about support I can access.		
I have been given an explanation as to why the interview will be audio recorded.		
I understand that what I say in the interview can be written in published journal articles, but I or my family will not be identifiable in any way.		
I would like a summary of the study results sent to me.		
I freely and fully consent to participate in the study, which has been fully explained to me.		
Once I give this consent I understand that I have the right to withdraw from the study within four weeks from the interview date, without disadvantage to myself and without being obliged to give any reason, and that the data collected will be destroyed.		
Participant's Name (BLOCK CAPITALS)		
Participant's Signature		
Researcher's Name (BLOCK CAPITALS)		
Researcher's SignatureDate:		

Appendix J Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE: Families' experiences of having a member of their family in a forensic mental health hospital

1.	How old are you?
2.	What is your gender? Male Female Other (please describe)
3.	What is your relationship to the family member in forensic mental health setting?
4.	How do you describe your ethnicity?
5.	What (if any) religion do you practice or have an association with?
6.	Are you
	☐ Working (full or part-time)
	☐ At college or university
	☐ In training
	☐ Unemployed
	☐ Not working due to long term physical or mental health problems
	Retired
	Other (please state))

Information and help line numbers

Resources to support your own wellbeing

If you need help and support with your mental health please speak to your GP.

If you feel that you want to take your own life please go to A&E or call an ambulance (999). If you want non-judgmental support and someone to talk to please call the Samaritans, **Tel: 116 123.** This is a free number and Samaritans are available 24 hours a day, every day.

You do not need to be suicidal to talk to the Samaritans; you can talk to them about anything that you find challenging and want to discuss it. See the website for more information: www.samaritans.org

For more information about mental health difficulties and ways of coping with these please see the MIND www.mind.org.uk and Rethink www.rethink.org websites.

SANE also offers emotional support and information to anyone affected by mental health problems via their helpline, email services and online Support Forum where people share their feelings and experiences. Website: http://www.sane.org.uk. The helpline is open everyday from 6pm-11pm. Tel: 0300 304 7000.

If you are worried about your family member in hospital please speak to the contact person at the hospital.

Resources to support families' experience of having a member of the family in a forensic setting

Websites

Action for Prisoners' and Offenders' Families works for the benefit of prisoners' and offenders' families by supporting families who are affected by imprisonment. On the website there are leaflets and a newsletter available for families: www.familylives.org.uk/about/our-services/action-for-prisoners-and-offenders-families/

Mediawise provide free, confidential advice and assistance for members of the public affected by inaccurate, intrusive, or sensational media coverage. Website: http://www.mediawise.org.uk

Partners of Prisoners (POPS) provide information and support to the families of offenders from their earliest contact with the Criminal Justice System (CJS), through to release and beyond. Website: http://www.partnersofprisoners.co.uk

Prisoners' Advice Service is a charity offering free legal advice and support to adult prisoners in England and Wales. Website:

http://www.prisonersadvice.org.uk

Victim Support is an independent charity helping people cope with the effects of crime, by providing free and confidential support and information. Website: https://www.victimsupport.org.uk

Helplines

Offenders' families helpline is a freephone helpline available for advice and support on all aspects of arrest, going to court and prison. It is available Monday to Friday from 9am-8pm, and Saturday and Sunday from 10am to 3pm, The telephone number is 0808 808 2003. Website:

http://www.offendersfamilieshelpline.org

Pact is a national charity, which supports people affected by imprisonment. It provides practical and emotional support to prisoners' children and families, and to prisoners themselves. The Freephone Helpline operates between Monday to Friday from 10am to 5pm: 0808 808 3444 Website:

http://www.prisonadvice.org.uk

• Online Forums

Prison Chat UK is an online community forum for anyone with a family member in a forensic setting. Website: http://www.prisonchatuk.com

Appendix L Coded Transcript Excerpt

I: What was it like visiting? P8: Visiting was quite good in both centres (MSU + visiting LSU). I: At the <msu>? Difference on FM on hospital location get there. I didn't know this at the start that he would</msu>
LSU). I: At the <msu>? Difference on FM on hospital location get there. I didn't know this at the start that he would</msu>
I: At the <msu>? Difference on FM on hospital location get there. I didn't know this at the start that he would</msu>
P8: It was quite good I can just walk down 2 roads and get there. I didn't know this at the start that he would
get there. I didn't know this at the start that he would
be put there. It was just a suggestion that was made
as well as other places. Can't remember off the top of
my head. It was ideal for me and I could go up and see
him.
Sometimes it was hard for me to go there. It was hard Challenges of
for me to go there not only cos of <su> but because of environment</su>
looking at the other people that was there as well. And
seeing some that were so much worse mental wise
than <su>. It was hard to look at.</su>
It is still very, very hard to see. And that's why I find it
very hard to go to any of them. I really go there and go visits
there with "oh God that's where I've got to go today".
You know we speak on the phone nearly every day but phone frequency
to actually go there
I: How do you do it? What FM need to do
P8: Have to give myself a good talking to. I do actually- to help stay in
it is a build up, it is a build up of and then you are contact with SUs
actually walking out the dooractually getting out of
bedand for me because
I suffer from anxiety as well so I probably wont sleep MH difficulties
properly that night knowing where I'm going the next
day.

By the time I get there my eyes are half way down my	Emotional impact of
face and I'm a bit of a state but I don't go as often as I	visiting
should – I can't go up there all the time.	
I: What's it like when you're there?	Emotional impact of
P8: Yes it is very stressful to see my son there	visits
I: How do you do that?	
P8: Circumstances and that's the way it is	
I: What kind of things do you tell yourself?	Sole responsibility
P8: "I have to do this". I have to do this number 1 "I	
have to do this because I am his mother". His father's	
not here anymore and I'm the only person he's got.	
He's got brothers and sisters but I am the only parent	
that he's got that's alive. I keep saying why did you	
have to die now big X you know why couldn't you be	
around?	
I: When did he die?	Death
P8: He died about 8 weeks before this happened.	
Before <su> got put inonly a very, very short time.</su>	
Might even have been less than that because it was a	
very short time. His death is a lot about him being in	
there now	
I: That sounds difficult	
P8: No it wasn't a huge trauma. It was a fact – his dad	
dying.	
I: What is it like seeing other patients?	Challenges of
P8: Yeh I sit down there and I see. I sit in <lsu> and I</lsu>	environment
sit in the reception waiting to go through. I see all	
these people and they are soI just want to cuddle all	
of them. And I just think no one ever thinks about	
these people and they are just sitting there. Everyone	
just walks past WH like its maybe a YMCA or	
something and it's not. It's a place where people are	
suffering they are mentally suffering. Its most upsetting	
that peopleapart from people who are their private	
peopleno one really cares.	
1	<u> </u>

I: Has it got any easier?	Doesn't get easier
P8: No it doesn't get any easier. That part of it never	
gets any easier.	
<su> in his own self that gets easier I can see a big</su>	Progress
improvement in him. A big, big improvement. With his	
speech the way he is the way he reacts to people I can	
see a big, big improvement in <su>. That I can see.</su>	
I: How does that make you feel?	Experience of SU
P8: Yeh I feel good when I see that.	progress
I: What's your involvement in his care?	Types of meeting
P8: I know exactly what's going on up there because	
he tells me all the time. I've been to a few meetings up	
there I was there a few months ago at a meeting. With	
a lot of people I can't remember their names at the	
moment.	
I: Was it a CPA? Or a Ward round every 2 weeks?	
P8: I think it was just a general this is how he's doing.	
Yeh that's what it was. Yeh. Yeh that is what it was	
CPA – I got invited to that and I went to that. Basically,	
sat and listened to what was going on. Basically, what	
I thought that was.	
I: What was it like?	Experience of
P8: It was ok. It was really what I expected.	meetings at hospital
I: It met your expectations?	
Yeh.	
I: Was <su> involved in MH services before</su>	
prison?	SU journey
P8: No it was more. It was justhe went to hospital for	
appointments with his consultant. It was no MH about	
it. It was allappointments.	
I: How have your experience of a CPAs been?	Experience of
P8: Well they made me very welcome. And they talked	meetings
about <su> and what he is doing and how he is</su>	
progressing since his last meeting. And if they had set	
goals at the last meeting has he met those goals. Have	

I got any goals that I want him to meet? They did bring	
me into the meeting I wasn't just there listening to it	
they did bring me into it. It was a good informative	
meeting.	
I: Did they ask about you?	How are you?
P8: I don't think so	FMHH not asking
I: Has any services ever asked how you are?	how FM are
P8: No	
I: Do you have contact with members of staff at	Being informed of
hospital?	meetings
P8: Unless I got invited to a meeting the only person	
who told me about it was <su>. Via him was involved</su>	
because we was talking about it.	
Two ladies come here might be about a year and half	Clinical interview/
ago to speak about <su>we sat and talked about</su>	Experience of
<su>. Never heard another word from them since.</su>	clinical interview.
One used to run <msu> and one was a social</msu>	
workernot too sure off the top of my head. I thought	
maybe something might have come of it.	
Wanted to know all about his childhoodup to date	
<su>. Very much into his dad and me. I was like this</su>	
is nothing to do with anyone else because that's split	
up. <su> was couple of monthshe was only 6</su>	
monthshe wasn't knowing of nothing. There was	
we were both in contact with his life all of his	
lifethere washe washe brought him to	
Cambridge. That was good because <su> has asthma</su>	
and he was having a lot of asthma attacks here. So he	
went to Cambridge which was all goodI went up to	
see him and he brought him herethat was all good.	
To the fact that he was a lorry driver if he had an	
overnight job he would sleep here on the sofa.	
I: How was that meeting?	
P8: I really couldn't get to the why. If I had the why	
about the whole thing it would be nice but I didn't get a	

	1
why about it. Didn't know what it was all about and	
haven't heard a word since	
I: How do you feel about that?	
P8: I thought it was pretty stupid if you are going to	
take someone's time and sit and talk to them. I know	
why you are here because you explained why you are	
here. They came here because they are seeing to	
<su> for goodness of <su> but what came out of it</su></su>	
it was nothing. I would have liked a letter saying	
we're not going to carry on with thisthe regime is	
different nowbla bla blabut nothing At all which	
I found odd. That was the staff from <msu>. I just</msu>	
found that very strange.	
I: How long did <su> spend in <msu>?</msu></su>	Time spent in
I: How long did <su> spend in <msu>? P8: Quite a few yearsmaybe 9 years.</msu></su>	Time spent in MH/FMHH
P8: Quite a few yearsmaybe 9 years.	
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>?</lsu>	
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had</lsu>	
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing.</lsu>	MH/FMHH
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day?</lsu>	MH/FMHH Communicating
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day? P8: There was one that I was told about but I was on</lsu>	MH/FMHH Communicating support for families
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day? P8: There was one that I was told about but I was on holiday at the time. There was something recent as</lsu>	MH/FMHH Communicating support for families
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day? P8: There was one that I was told about but I was on holiday at the time. There was something recent as</lsu>	MH/FMHH Communicating support for families
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day? P8: There was one that I was told about but I was on holiday at the time. There was something recent as well but I couldn't go</lsu>	MH/FMHH Communicating support for families by FMHH
P8: Quite a few yearsmaybe 9 years. I: How long at <lsu>? P8: It might have been there 9 and there 5. Yeh had nothing sinceno lettersno nothingnot a thing. I: Have you attended family network day? P8: There was one that I was told about but I was on holiday at the time. There was something recent as well but I couldn't go because I was looking after my sister who died two</lsu>	MH/FMHH Communicating support for families by FMHH Death of family

Reflections

Thoughts post 1st interview

P1 expressed how she was very willing in participating in the research because she is familiar with academia. I think I was anxious as it was my first interview and didn't prevent her from talking quite a lot about the achievements of her family. It was apparent she was a very proud mum.

I sensed a real need for her to present a really "lovely" version of her son naming him as the "most intelligent" and that "the other children think I love him the most". This made me think about her beliefs, and about how others may view her and her son, including stigma and blame around families and mental health, she may have assumed that I also hold them and therefore protecting him and her family, although I do not hold them. I thought perhaps cultural differences between myself and her may also be causing her to amplify the impression of how "good" her son was.

Her beliefs around the medical profession were apparent, praising them where possible, I sensed a felt lack of appreciation for the rest of his clinical team. I think as a trainee psychologist this jarred with my beliefs about the medical model and I found myself not exploring what she was meaning by her references to the medical profession.

Methodological thoughts

The interview was longer than expected, perhaps as it was my first interview and I was not so familiar with the questions. However, too much time was spent on the wider family's current life- but it also felt that this is where she was most comfortable

It is apparent more prompting questions are needed and some are too difficult to understand. She didn't understand my question about "how she keeps going" and so may change this to how she and the family take care of each other. I was thinking that this maybe a language issue, as English was her second language, but I also realised that this is also colloquial language, and using this

can impair communications.

I think I prompted 'religion' as an example of what she might find helpful, within the interview. It was a leading question, so need to think about altering that question for it to make sense to others, without prompting.

Trustworthiness/Audit of ideas

Ideas that came from the interview

- Own and husband health issues- made me think about how parents must cope with aging health issues and the other challenges faced that are not directly associated with SU.
- Information- Very strong emotions of how she sometimes isn't given information, ideas around consent were brought up. She wants more information from staff at hospital related to SU and education about mental health conditions
- Currently supported in Family therapy- which may not be the case for the rest of interviews.
- Felt a real contrast to how the SU is in hospital compared with his siblings in different countries, all 'successful' and with families
- Stigma from community- was the most emotive part of interview. I
 wondered whether she had attended the mosque prior to the SU index
 offence, especially as her husband was so involved in it. Perhaps this is
 my perception of what religion is and that private practice has always
 been the way she practices her religion.

Thoughts prior to second interview

Using adapted questionnaire.

Went in to the interview aware of the biases and stigmas around mental health that the participant may believe I hold. Held in mind the idea that stigma may have an impact in the family member's experience of having a SU in a FMHH.

Reminded self to not ask leading questions generally, and especially regarding self-care.

Acknowledge that family therapy is given to a minority of families and therefore

is likely to have a different experience.

Thoughts post second interview

P2 was rather guarded in her responses when talking about the family and her own experiences. She was more willing to discuss how services could improve for family members. She spoke a lot about stigma, including stigma from family members. She spoke in the third person at times and I felt was slightly detached from the emotive content.

First 2 interviews with well educated women from 2 different cultural backgrounds. Both have had lots of contact with FMHH.

Said that religion doesn't matter, but does attend church? Should have asked questions about relationship to religion and whether this changed as a result of SU being admitted to FMHH.

P2 also gave me lots more information about the family post-interview which I interpreted as not wanting these details to be included in the data.

Methodology

A different interview to the first as she spent very little time in talking about the family and more about contact with services.

Should have asked about clarification on things said, it made sense at the time, but, when listening back to the recording it didn't, and therefore, I couldn't include some responses.

This interview gave me a lot of material about relationship with services and provided me with further prompting questions about this in later interviews.

Trustworthiness/ Audit of ideas

- 'Loss'- felt really big, as she repeatedly spoke of 'loss' in relation to the SU lost life, the missing of the person and the number of times he has been in hospital. Feels like a change in the family.
- Helplessness and lack of control in relation to the MH and service intervention were really apparent.
- Stigma and mental health even more apparent in this interview than the

- first. A lot of talk about the need for awareness of mental health generally.
- Spoke a lot about having to "learn the system"- which I had not thought about prior to research and maybe worth thinking about in relation to how long SU have spent in hospitals.
- Lots of ways of coping including "being present" and involved in SU care.
- P2 spoke of the support of her mother and cultural differences in ways of perceiving and coping with mental illness but how this has been helpful.
- Gave lots of ideas for services for Family members counselling, independent support, continuous support, group activity, carer support for resources and company from other family members, hospital to ask how family members are. Future interviews- maybe ask to refine what would be best to meet needs as a family member.

Appendix N Example Of Coding Table From Global Theme: Family Processes.

Please note not all codes are represented for each theme

Organising theme	Basic theme	Code	Excerpt1
Keeping the	theme	Code	P1: after all he's my son you love
family	Parental	I'm their	your children with all their faults
together	duty	parent	(190)
together	duty	parcit	P8: "I have to do this". I have to do
			this number 1 "I have to do this
			because I am his mother". His
			father's not here anymore and im
			the only person hes got. He's got
			brothers and sisters but I am the
		Sole	only parent that hes got that's alive.
		responsibility	(103)
			P11: No not really. Because <su></su>
			is not here with us I don't feel, we
			care we care very much about him
			but I don't feel like we are caring for
			him at the moment. I mean I would
		Carer role?	like to be but he is in hospital. (52)
			P2: I suppose holding, holding the
			situation together, holding <su></su>
			together, myself, pretending things
			are normal, let's just carry on but
			they're not you know at some point
			umm things just become very
			fragile, don't they? But it's not right
			it's not right and your try and glue it
	Holding	Holding	back together or hold it and you
	the family	everything	know it's not going to happen so
	together	together	you have to just let it go. (216)
		Drave food	P9: You have to put on a brave face
		Brave face	(436)
		Protocting/ou	P9: I was sort of pretending to the other children that I was ok,
		Protecting/su pporting the	because I didn't want them falling
		other children	apart. (104)
		Protect the	P1: Please don't take it against my
		SU	son (151)
			P11: I just hope that in time he will
			come to understand why we did it
		Hope FMs	a and forgive us for it at the
		mend	moment I don't see that ever
		relationship	happening.
	Factors		P1: I pray for my children every
	that		night and I say rosary a thousand
	influence		times for each child pray and I say
	families'	Faith	that this is from that child to

abilit adap		GodAnd I pray for <su> and I believe in prayer. (404)</su>
	Keep	
	going/do normal	P7: In one sense you have just to got to get on with it really. (269)
	Me activities	P2: And for me its yoga once a week its piano, its cranial therapyI have designated things that are just for me and I suppose that helps. (155)
		P10: I work 2 days a week and
		that's good. Although driving home
		is so much worse than driving in.
	Work	(514)
		P1: I don't remember the things that
	Don't think	hurt me. I try and get rid of them.
		P7: I kind of try and take it one day
		at a time. I don't try and think too far
		ahead. I just kind of think one day at
	Day to day	a time (425)
		P11: I suppose I was a bit of a
		fighter and I was never going to give
	Resilience	up on him (355)

Appendix O Initial Candidate Themes Example

There were 5 original global candidate themes: Struggles with the system, coping, emotional impact, family dynamics, support from services. These were then restructured to do 2 global themes: Negotiating systems, Family Processes. The rationale for doing this was that the themes were not distinct enough, with many overlapping ideas.

Global theme	Organising theme	Basic theme	Codes
Struggles with the system		Communication with the hospital	Contacts/ Sources of info (nurses, clinical team, social worker)
			Lack of info
			Chasing information
			Barriers to communication
			Timing of contact?
	Difficulties with services pre -admission	Problems accessing services	Witnessing deterioration
			Inappropriate tx
			Initiating transfer/admission
			Failure of system
			Being an adult
			Feeling stuck
		Contact with legal system	Visiting prison
			Police
			Courts and solicitors
	Relationship with service	Trust	Trust (P1)
			Lack of trust and
			confidence in system
			Lied to
		Deliefe of how EM are	Nobady listors /#bstf
		Beliefs of how FM are	Nobody listens (threat of media)
		thought about by hospital	Treated as a hindrance
			Kept at a distance
			No consideration

		Nobody understands FM
		Non-existent
Ways of maintaining involvement	Formal- CPA/ward round/tribunal/ interviews	Meetings at hospital
		Being informed of meetings
		Experience of meetings
		Not being involved
		Clinical/developmental interviews
	Informal- phone/visits	Phone/visiting frequency
		Challenges of visiting
		Location makes it easier
		to visit
		Abuse on phone/visits
		Impact of phone calls and visits
		Absconding
		No contact/changeable contact
		Comfort/advice offered to SU
	Want to be involved	Collaborate with us
	vvani to be involved	We just want to help
		we just want to help
	Progress of SU	Lack of progress
	1.10g.000 01 00	Stuck/not moving forward
		Progress
		Want SU to do something
	Brief relief	Safety
	Brief Teller	Relief knowing where he is
		Treatment/getting help
	Beliefs about staff and treatment	Non-caring staff
		Helpfulness of staff
		Limitations of medicine
		Psychosocial approach
		Temporary approach
	Processes and procedures	Time
		Location
		Security

Appendix P

Excerpt from Research Journal: Audit Trail Restructuring Of Initial Candidate Themes And Hierarchy

Here are 2 examples from the research journal which supports the audit trail of how themes were initially hierarchically structured and then restructured (this restructure was later refined).

Example 1: Initial 5 global themes restructured to 2

5 global themes were initially created:

- 1. Struggles with the system
- 2. "Coping"/ How I got through
- 3. Family dynamics
- 4. Support from services for family members
- 5. Emotional Impact

2 global themes resulted after restructure and collapsing of these themes:

- Family Processes (generally a collapse and form of family dynamics, coping and emotional impact)
- 2. Negotiating Systems (generally a collapse and form of struggles with the system and support from services for family members).

Examples of audit trail during restructure:

- 1. changes made to the global theme "Emotional Impact":
- The global theme of "Emotional Impact" was dismantled.
- 'Loss' was inputted in to the global theme of "Family Processes", it was
 felt that 'loss' was a process the family were having to manage and
 therefore fitted within this global theme.
- "MH impact" was collapsed across themes connecting to what the distress was associated with emotion was associated with. The code "Not coping" went into "Families feeling stuck in systems". The basic themes of "pain" and "fear" were absorbed by theme of "family relationships" within "family processes".

- "Powerlessness" was divided into 2, powerlessness related to the families felt lack of control related to the SU mental health or lack of control and helplessness in relation to the services. It was thought "powerlessness" as a construct encompasses the whole analysis.
- 2. The changes made to the global theme: "Coping/ How I got through"
- This global theme was collapsed into the 2 re-constructed global themes.
 "Parental Duty" was moved into "Keeping the family together" as it felt it wasn't a "coping" strategy but a given role that the families embraced as a way of supporting the family.
- "Support of Others" was re-named "social network" within "family processes", as it was thought that this theme wasn't about support necessarily but families' relationship to friends and the community, which weren't always supportive.
- "Personal coping" was subsumed by "Keeping the family together" as it
 was how family members were trying to take care of themselves in order
 for themselves and the family to stay "strong" and together.
- "Resilience" was formed in to a code rather than a theme and inputted in
 to "Holding the family together", as they were internal-qualities that family
 members described when they were talking about how they maintained
 this. "Hope" was collapsed and inputted across the 2 global themes,
 dependent on where the family members 'hope' was directed.

Example 2: How 2 global themes with 29 basic themes were restructured with 15 basic themes

Family processes

This changed from 12 basic themes to 9 basic themes by changing the following:

"Powerless of SU MH" collapsed into "Loss of SU", as it describes the FM felt powerlessness in relation to the SU 'loss' of self.

The themes of "Contact", "Emotional Impact of contact" and "Barriers to maintaining involvement" were collapsed in to a basic theme of "FMs ways of maintaining involvement in SU life whilst in a FMHH" as it was thought they were describing one another.

Negotiating Systems

This changed from 17 basic themes to 6 themes by changing the following:

Instead of different themes describing the different contacts FMs have with different systems e.g. legal, involvement in meetings around SU care, it was collapsed in to one basic theme of "FM contact with systems".

"challenges accessing treatment" and "temporary relief" were collapsed as one theme "accessing treatment for SU", as the former described the difficulties accessing treatment of the SU and later described the thoughts and feelings of the FMs once treatment was accessed.

"Struggling with systems" is a theme that encompasses what was "FM feeling stuck in system" and "Witnessing progress of SU". The rationale behind this was that families feel stuck in systems as a result of witnessing a lack of SU progress (and other things) and this relationship felt strong enough for it to be one theme.

"Lack of trust in services", "FM beliefs about care", "Beliefs of how FM are treated by services" and "FM felt powerlessness with services" were collapsed in to "FM perceptions about services" as they are all FMs' beliefs about services, treatment by services, and emotional impact of these perceptions i.e. powerlessness, although lack of trust dominates within this theme.

"Support from Services" now encompasses the different versions of support available for FMs, the lack of support available and ideas suggested by the FMs of services that they would like to support FMs.

Appendix Q

Description Of Themes

A rich description of themes that emerged from the TA are presented here. These can be used to support the transferability of the findings.

Negotiating systems (organising)

This theme describes families' interactions and experiences with health, mental health (MH) and criminal justice systems (CJS), resulting from the Service User's (SU) complex and lengthy involvement with services. Families faced numerous challenges in contact with these systems; these had significant emotional and practical impacts on the family and their beliefs about services which in turn, impacted the way in which they related to the system.

This theme also includes the ways in which families needed to negotiate systems to meet their own needs, the challenges in accessing appropriate services and the families' suggestions for services so their needs can be met.

Challenges of interacting with systems (basic)

This theme includes all the challenges that families faced throughout the SU journey, from the onset of the MH difficulty.

Families faced multiple challenges in accessing MH support for their child and throughout their child's journey, including; navigating and adapting to complex systems and bureaucratic hurdles, accessing and communicating with health professionals, and perceived inadequate involvement and opportunity to support decisions around SU care and treatment concerns.

Impact: "a lifetime of struggle" (basic)

This theme encompasses what families needed to do to meet these challenges and the subsequent impact on them.

The impact of the challenges faced were considerable. Families wished that MH treatment had been secured promptly for the SU, in order to lessen or prevent their violent behaviour, and/or endure the challenges of negotiating systems.

Families required persistence when accessing support for, or information regarding the SU, available resources, and described themselves as "fighting" the system. Some families expressed relief and hope regarding their child's admission to a FMHH; others were concerned.

Many families felt 'blamed', i.e. that services considered them responsible for the SU's situation and deliberately distanced from SU and the FMHH. Consequently, families felt painfully disconnected from the SU, powerless, devalued or unrecognised by services. These impacts meant that the relationship between families and FMHH lacked trust, resulting in further challenges.

Services support for families (basic)

This theme encompasses service's provision for families, lack of appropriate support and families' suggestions for services. It follows the "lack of recognition by services", theme but is distinct as it focuses on how families wanted to be recognised, in addition to their "caring role".

Family processes (organising theme)

This theme recognises that families differ as do their relationships with the SU. Families changed as a result of the SUs' mental health and associated admissions to services. Families fractured in different ways and became unable to transition as a family together. Irrespective of whether they fractured or the extent to which they fractured, families attempted to remain connected. Families' abilities to adapt to challenges were influenced by different coping strategies.

Families are different (basic)

Families interviewed varied in relation to size, composition, marital status and geographic distribution. Seven of the eleven families considered themselves 'close' family; others didn't comment on the quality of their relationships.

This theme also encompasses the differences between families in regards to the SU violence and aggressive behaviours towards family members. Some families did not report any violence, for others violence towards a family member was the reason for admission to a FMHH, and in some families this aggression by the SU continued, or only occurred whilst the SU was receiving treatment.

Families fragment (basic)

This theme encompasses how families changed as a result of the SU MH and admissions to services. It emphasises that families were unable to transition together because of their felt loss of their family member, relationships ending, members navigating different life paths, unexpected transitions resulting from the SU being unwell, and, expected transitions that families had to adapt to whilst the SU was in a FMHH.

'Loss' of a family member (basic)

All families felt that they lost a family member due to the development of MH difficulty, and this felt 'loss' was exacerbated when they were transferred into a secure service. Families felt helpless and powerless in the light of the SU's distress and not being able to fulfil parental norms.

'Loss' of family coherence (basic)

Families became further fractured, losing their sense of coherence. Within some families, relationships ended, in others, parents and siblings developed alternative life paths. Initially these changes are a response to their family member's mental health, exacerbated by being a victim of, or witnessing, violence and the physical separation of their family member entering a FMHH. Thus, families do not transition together coherently.

Other family transitions (basic)

Families needed to adjust to other challenges as a consequence of having a member with MH difficulties and violent behaviour e.g. physical injury, moving home as a result of violence, leaving work because of family responsibilities, funding private health care. These were additionally disruptive, difficult and unexpected events in family life.

Additionally, families also had to manage traditional life transitions including; death, moving house, ageing. Many were also challenged by their own MH and

physical health difficulties. Some parents understood this to be a result of, or exacerbated by, traumas they had faced.

Holding the family together (organising)

This theme encompasses the roles undertaken, abilities, and efforts of families to manage relationships within the family and maintain a sense of coherence. The theme encompasses how families kept their relationships intact including how they stayed connected to the SU. Parents emphasised their role and their responsibilities in meeting the demands of their families' internal and external pressures.

Holding the families' relationships together (basic)

This theme captures the ways in which families developed strategies to keep the family connected and defended from internal/external stressors, so reducing negative impacts. Families did this by 1) using their resources to support themselves, 2) parents protecting their relationships with their children and partners, hoping that their family will repair. 3) protecting from intra and extrafamilial stigma.

Keeping the service user within the family (basic)

As noted the relationship between the SU and family was tested in many ways. Families did three things to sustain this relationship, 1) stayed in contact with the SU 2) made sense of the violence and forgave the SU 3) contained their feelings about the SU and associated challenges.

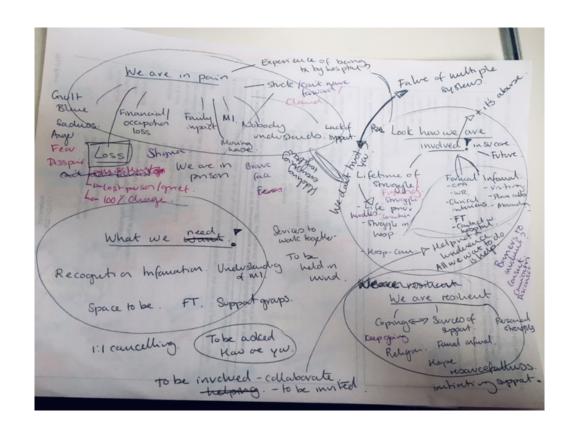
Parental duty (basic)

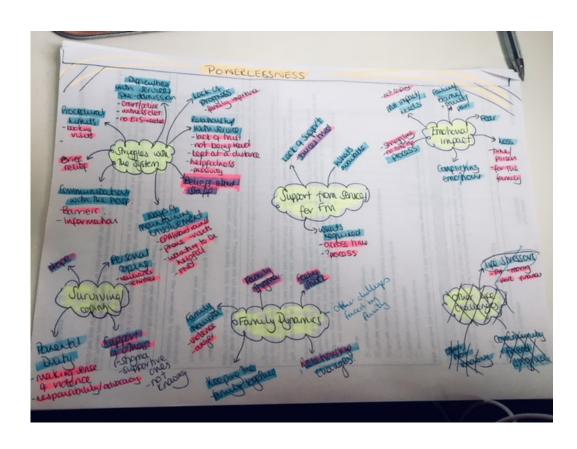
'Parental duty' describes the implicit and embraced role that parents undertake, although some interchanged 'parent' and 'carer' labels. Parents felt they were the only "real" social contact the SU had, with a responsibility to advocate for their child and absorb the consequent stresses. They emphasised that meeting the demands of the families' external and internal challenges was their role; this belief gave them strength to persevere.

Factors that influence families' ability to adapt (basic)

This theme acknowledges the strategies and resources families used to maintain their wellbeing when challenged by having a member in a FMHH, including; personal characteristics, behavioural and cognitive coping strategies as well as use of religion and social support.

Appendix R
Diagramming Connections Between Themes





Appendix S NHS Health Research Authority Ethics Approval



Miss Sarah Williams Trainee Clinical Psychologist

Email: hra.approval@nhs.net

12 October 2017

Dear Miss Williams

Letter of **HRA Approval**

Study title: A Critical Realist informed Thematic Analysis: Families'

experience of the process of adjustment when a family

member is in a forensic mental health hospital

IRAS project ID: REC reference:

Sponsor University of East London

I am pleased to confirm that <u>HRA Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read Appendix B carefully**, in particular the following sections:

- Participating NHS organisations in England this clarifies the types of participating
 organisations in the study and whether or not all organisations will be undertaking the same
 activities
- Confirmation of capacity and capability this confirms whether or not each type of participating
 NHS organisation in England is expected to give formal confirmation of capacity and capability.
 Where formal confirmation is not expected, the section also provides details on the time limit
 given to participating organisations to opt out of the study, or request additional time, before
 their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment

Appendix T NHS Research Ethics Committee Approval



Research Ethics Committee

HRA NRES Centre Manchester Barlow House 3rd Floor 4 Minshull Street Manchester

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

11 October 2017

Miss Sarah Williams



Dear Miss Williams

Study title: A Critical Realist informed Thematic Analysis: Families'

experience of the process of adjustment when a family

mber is in a forensic mental health hospital

REC reference: IRAS project ID:

Thank you for your correspondence of 03 October 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC at a meeting held on 03 October 2017. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further

Appendix U Distress Protocol

The conversations within the interview maybe distressing to the participant. The following procedures have been put in place to prevent and respond to this should it occur:

Prevention protocol, to reduce distress of the participants:

- The Local Collaborator who knows the family identifies them as 'suitable' participants i.e. the clinician knows and is in contact with the family; the family are not in acute distress.
- Local Collaborator requests updates from the clinical team about the 'suitability' of the family prior to contacting them at engagement i.e. letter. The Chief Investigator also requests updates from the Local Collaborator about the 'suitability' of the family prior to the interview.
- 3. The participants are not directly asked about the violent or criminal behaviour of their family member during the interview.
- 4. Chief Investigator has had prior clinical experience in working with distressed families and is supervised by qualified and experienced Clinical and research Psychologists'.
- 5. Written debrief material will be given prior to the start of the interview should the interview terminate early for any reason. This directs family members to different types of support should they want to use it. A verbal debrief will be given at the end of interview.
- 6. Participants are made aware before the interview that should they become distressed they can terminate the interview at any time.
- 7. Interviews will be held on days on which the Local Collaborator is at work and in the hospital, should the Chief Investigator need their support for any reason.
- 8. The Chief Investigator is familiar with the policies and protocols of the hospital sites including managing aggression, conflict and physical intervention.

Response protocol, should participants during the interview become upset:

1. If the participant has not already terminated the interview, the Chief Investigator will do so, if it is perceived that the participant is upset.

- 2. The interview will be terminated by switching off the recording device and informing the participants that the interview is terminated.
- 3. The Chief Investigator will calm the participant using their clinical skills.
- 4. The Chief Investigator will ask the participant if they want the Local Collaborator to be told of their distress and if they wish for a call back within 5 working days OR the Local Collaborators name and number is given to the participants should they want to follow up any concerns.
- 5. If the participant requests for the Local Collaborator to call them, the extent of the call is to encourage the participant to seek help form established networks of support e.g. GP.
- 6. Chief Investigator will handover risk concerns i.e. the participant discloses immediate and significant risk to self or other, as appropriate, to identified Local Collaborator. This will be discussed with the participant before any handover is given, unless inappropriate e.g. escalate harm to participant/victim.

Response protocol, should participants become verbally abusive or physically aggressive towards the Chief Investigator:

The interview will be terminated. If verbally abusive, the Chief
Investigator will inform the participant and request that they leave
hospital grounds and request escorts if necessary. If physically
aggressive the Chief Investigator will follow the alarm procedures of the
hospital.