EXPERIENCES OF FAMILY MEMBERS OF ADULT CHILDREN IN FORENSIC SERVICES AND THEIR INTERACTIONS WITH MENTAL HEALTH PROFESSIONALS.

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Abstract

The importance of family caregiver involvement in (secure) mental health services has been increasingly recognised and there is a wide consensus that family caregivers should be seen by clinicians as partners in the care of patients (Harvey & Ramsay, 2004). Mental health carers however, especially those caring for relatives who are subject to compulsory care and treatment, often feel overlooked and marginalised, caring in complex circumstances with little or no support. This thesis focuses specifically on the views and experiences of parents of adult children in forensic mental health services. A structured review and synthesis of qualitative studies was undertaken to develop insight into the perceived level of involvement in care, from the perspective of family members of mental health service users. The review also examines family carers' relationships and engagement with mental health professionals. This highlighted that the practices of some professionals contribute to the distress experienced by caregivers in this marginalised group. The empirical research study, employed a qualitative design conducted within the framework of IPA, and explored what it is like for parents with an adult son or daughter with mental illness and offending background detained in a regional medium secure unit. Findings indicated that parents' experiences were characterised by a strained relationship with mental health services, accompanied by practical difficulties in getting help in the first place, and conflicting emotions felt in response to their unwell family member's continued detention in the forensic care setting. Following on from this, a case study describes brief family psycho-education in secure care and illustrates how staff in forensic services can collaborate with parents more empathetically and effectively.

Afterwards, the Family Relations Test, an instrument that assesses affective relations from the child's perspective is critically reviewed. The utility of this tool in clinical practice is remarked upon. In the concluding chapter, the ways in which service delivery and research can be influenced by 'giving a voice' to parents of forensic clients is explored, and implications of the findings are discussed with reference to the current recognition of family and social inclusion.

Publications

Finlay, G., Davies, J., Browne, K., & Ferguson, J. (2013, June). *It's a terrible battle: Experiences of parents with children in adult medium secure mental health care.* Paper presented at the Division of Forensic Psychology Annual Conference, Belfast, Ireland.

Preface

The overarching aim of this doctoral thesis is to articulate the experience of parents who support adult children receiving compulsory care and treatment in forensic services, and additionally report on how involved these informal carers feel in the treatment of their relative in secure care, as well as to explain what continued family involvement means for parents in this context. The thesis comprises four components: a systematic review; a large primary research study; a case study related to the research topic; and a critique of a psychometric measured applied in the case study.

In Chapter 1 a systematic review is presented which analyses the experience of informal carers' accounts of interactions with healthcare professionals providing support to family members with a mental health condition, in inpatient care. The review findings resonate with some of the issues highlighted in the extant literature, in particular, carers' feelings of powerlessness and being isolated from the care planning process, and the mental health professionals failing to recognise and value informal carers as individuals in their own right. The review suggests ways of improving and promoting carer involvement and advocating a partnership in care approach for families of persons with mental illness. The recommendations arising from the review findings sit comfortably with the recommendations of current UK government mental health strategy and professional guidance documents, regarding how services may meet the challenges of including carers of an individual with a mental health issue in the care planning process, as well as inclusion and support for family carers themselves, for their own sake.

Chapter 2 documents an exploratory study designed to gain a better understanding of the subjective experience of parents, who care for adult children with a diagnosis of mental illness and offending background receiving compulsory treatment and support in a medium secure unit. Research into this topic is scant, despite Governmental policy drive for mental health services to work in partnership with families and carers, including within forensic services. The study offers in-depth and illuminating insight into the experience of parents in this situation. A number of recommendations are suggested both in terms of direct work with parents, and also regarding how forensic services can collaborate with parents more empathetically and effectively.

Chapter 3 outlines a case study which involved individual assessment of an adolescent sex offender, and provision of carer support sessions attended by three of the client's family. The meetings were held to foster relations between the clinical team and the family, and to share information between parties in a structured and contained way. The case study offers a blue print for health and social care professionals in facilitating the more active involvement of families in the recovery/rehabilitation of their family members.

Chapter 4 critically evaluates The Bene-Anthony Family Relations Test, a psychometric measure which can explore the perceived emotional context of family relations, and was undertaken as part of the assessment of the adolescent sex offender case study.

Finally, chapter 5 concludes the doctoral thesis by presenting a discussion of the findings in relation to the previously stated aims. The outcomes in

chapters 1-4 are summarised and integrated and considered in light of the existing research literature. Implications from the findings of the study for both clinical practice and future research are commented on, together with the researcher's personal reflections in undertaking the research.

Acknowledgements

I would like to express my gratitude to all the parents who participated in this study for their willingness to give of their time and themselves in the quest to make their experiences more transparent, that this may benefit parents in similar circumstances. I would also like to thank the sons and daughters in the forensic medium secure unit where I spent my first placement, who gave permission for their parents to be contacted for the empirical research. I wish to offer many thanks to my clinical and academic supervisors, Dr Jason Davies, Professor Kevin Browne and Dr John Ferguson for their encouragement and guidance. I would also like to thank my systematic review supervisor, Dr Shihning Chou for her help and direction. Finally, to my family and my husband, I would like say a huge thank you for the abundant love, patience and understanding shown to me throughout this challenging yet satisfying, programme of study.

Table of Contents

Abstract 2
Publications 4
Preface 5
Acknowledgments 8
Table of contents 9
Table of tables 13
Table of figures 14

Introduction to thesis 15
- **Background and relevance to Forensic Psychology** 16
- **Medium Secure Mental Health Services** 17
- **Previous research** 19
- **The impact of mental illness on the family** 20
- **Burden and measurement of burden** 21
- **How families cope with the impact of having a relative with mental illness** 25
- **The impact of mental illness on the family over time** 28
- **Impact of detention** 31
- **The poor treatment of families and carers by professionals** 32
- **The impact of mental illness and forensic involvement** 33
- **Rationale for the present study** 38

Chapter 1: ***Family involvement in care of mental health service users and relationships with mental health professionals: a structured review and synthesis of qualitative studies*** **40**

- **Abstract** 41
- **Introduction** 43
- **Background** 43
- **Existing systematic reviews** 46
- **Aims and objectives** 48
- **Method** 49
- **Search strategy: sources of literature** 49
- **Search strategy: search terms** 50
- **Study selection** 51
- **Quality assessment** 56
- **Data extraction** 59
- **Results** 59

Description of studies **59**
Characteristics of included studies **60**
Integrating/synthesizing qualitative research **63**
Synthesis of findings **63**
Validity and Reliability **66**
Synthesis **66**
Summary of themes and sub-themes **69**
The problem of confidentiality **69**
The need of support **75**
Discussion **81**
Summary **81**
Implications for practice **83**
Strengths and limitations of the review **86**
Conclusions **88**
Link between systematic review and primary research study **90**

Chapter 2: ***Parental Perspectives: Being a parent of a son or daughter in adult medium secure forensic mental health care.*** **91**

Abstract **92**
Introduction **93**
Background **93**
Aims of the study **100**
Methodology **102**
Design **102**
Setting **106**
Participants **107**
Data collection **111**
Ethical considerations **114**
Data analysis **115**
Validation methods **117**
Characteristics of the lead researcher **117**
Results **119**
'Something's not right': onset of mental distress **121**
'Going through hell': experiences of violence and entering secure services **125**
'It's a terrible battle': relating with professionals **129**
'A very sad fact of life': caring with no end in sight **135**

Discussion **141**
Meaning of forensic caregiving **141**
Comparison to the literature **146**
Implications for practice **150**
Suggestions for further research **152**
Methodological considerations **152**
Conclusions **156**
Recommendations **157**

Chapter 3: ***Psychological Assessment and Intervention in the case of a Learning Disabled Adolescent Sex Offender and his Family Members.*** **158**

Abstract **159**
Links between research project and case study **160**
Definitions **162**
Theory and aetiology **162**
Theories of sexual offending in people with intellectual disabilities **184**
Ethical considerations **188**
Part 1: Case Presentation **189**
Definitional Considerations and Organisation Details **189**
Assessment Interview **192**
Psychometric tests **196**
Formulation **209**
Intervention **213**
Assessment of progress **215**
Discussion and recommendations **217**
Part 2: Family Intervention **220**
Client profiles and engagement **221**
Evaluation **223**

Chapter 4: ***Critique of the Bene- Anthony Family Relations Test.*** **226**

Abstract **227**
Introduction **228**
Overview of the tool **229**
Reliability **235**
Validity **237**

Uses in research 239
Discussion 240
Conclusion 243
Rationale for use of psychometric in case study 245

Chapter 5: Discussion 246
Summary of findings in Chapters 1-4 248
Systematic Review and Empirical Study limitations 254
Reflections 259
Conclusion and Recommendations 262

References 265
Appendix 1- Search Syntax 320
Appendix 2- Inclusion and exclusion form 325
Appendix 3- Screening of studies 326
Appendix 4- Quality assessment form 345
Appendix 5- Data extraction form 350
Appendix 6- Guidance for meta-ethnography 352
Appendix 7- Ethical approval document 353
Appendix 8- Participant information sheet for clinical team 356
Appendix 9- Participant information sheet for patient 359
Appendix 10- Participant information sheet for parent 362
Appendix 11- Invitation letter, patient copy 366
Appendix 12- Invitation letter, parent copy 368
Appendix 13- Parent follow up letter 370
Appendix 14- Participant consent form, patient copy 371
Appendix 15- Participant consent form, parent copy 373
Appendix 16- Interview schedule 375
Appendix 17- Adapted self-esteem scale 378
Appendix 18- Adapted Impulsivity scale 379
Appendix 19- Adapted Ruminations scale 381
Appendix 20- Sexual attitudes and knowledge scale 383
Appendix 21- Questionnaire offence related attitudes 384
Appendix 22- Bene- Anthony Family Relations test items for older children 397
Appendix 23- Working in partnership with Psychiatrists and Carers 401

Table of Tables

Number	Title	Page
Table 1	Inclusion and exclusion criteria	54
Table 2	Grading of study quality	57
Table 3	Quality appraisal process applied to included studies	58
Table 4	Characteristics of included studies	61
Table 5	Themes identified in each study	68
Table 6	Characteristics of family caregivers	111
Table 7	Summary of themes	120
Table 8	Client's distribution of feelings towards family members	198

Table of Figures

Figure	Title	Page
Figure 1	Flow chart summarizing search strategy	55
Figure 2	Pathway model of informal caregiving by parents of adult children with mental distress living in a forensic setting	145
Figure 3	Schematic representation of family members' experiences of caregiving and their relationship with professionals in mental health services	253

INTRODUCTION

Background and relevance of the research to Forensic Psychology

This study arose out of an interest which developed from my placement experience during 2011-2012, at a single regional inpatient service in Northern Ireland, for people with mental illness who require intensive treatment and rehabilitation within a structured secure therapeutic environment. Within my role as Forensic Psychologist in Training in the medium secure unit, I met some of the families of individuals who had been detained in the inpatient setting, and as I listened to mothers and fathers describe their (often difficult) experience of visiting their child, I was moved by the challenges they faced. I wondered what the 'mental health system' looked like to parents who have a son or daughter in secure care, and what their responses were to their child's mental health problem, the ways in which they experienced contact with health professionals, and how different the meanings of these experiences must have been to mine. Hearing one touching story in particular, told by a parent couple after their daughter had refused to see them at her family visit, and subsequently, finding a deficit in the literature concerning the experiences of persons who have a loved one in forensic care, became the driving force for the research undertaken.

The main objective of the study is to gain a better understanding of the subjective experience of parents, who care for adult children with a diagnosis of mental illness and offending background receiving compulsory treatment and support in a medium secure unit.

The project is exploratory in nature in order to gain as rich an understanding as possible. Although a substantial amount of literature is available regarding the impact of mental illness on carers and other family members,

there is little research into the emotional impact of having a son or daughter detained in a forensic setting, and none into the meaning families attach to the experience of caregiving for a relative being formally cared for by professionals in medium secure services.

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

Medium secure mental health services

The present study was undertaken with parents who have a son or daughter receiving care and treatment in a regional medium secure facility in Northern Ireland, which is a part of the United Kingdom. Therefore, to situate the research site within UK forensic mental health services a brief description is provided of the development and function of medium secure services, along with statistics in relation to the forensic service user population.

Medium secure forensic mental health services were developed following the recommendations made in the Glancy (Home Office, 1974) and Butler (Home Office, 1975) reports to provide 1000 to 2000 medium secure beds in the UK. The aim of creating medium secure provision was to alleviate the pressure on high security hospitals and to improve rehabilitation by locating secure services within the community. Users of medium secure forensic

services were expected to progress towards discharge within eighteen months (Home Office, 1974). Thus it was not envisaged that service users would be detained for any great length of time within medium security, rather that medium secure services would provide an assessment, and rehabilitation step down service. However, the throughput of services has been considerably slower than originally expected by both Butler and Glancy (Home Office 1974; Home Office 1975). In 2004, over half of forensic service users were detained in medium secure forensic mental health services for less than five years, with 18 per cent held for between ten and twenty years (Rutherford & Duggan, 2007). The prolonged detention of some service users was reflected in the data collected during the present study, with one couple advising their daughter had been an inpatient for seventeen years without any gaps in secure care.

Of the proportion of people detained under Part III of the Mental Health Act (patients concerned in criminal proceedings or under sentence) 78% of these patients are men. Reflecting the pattern of compulsory detentions, the number of mentally disordered offenders detained as restricted patients in hospital has increased steadily since 1999, with 4300 restricted patients in 2009 (Ministry of Justice, 2010). Restricted patients have an older age profile than the general prison population with 4% less than 20 years of age; 89% aged between 21-59 years and 8% over the age of 60 years. Although no statistics are available for relationship status in the restricted patient population, other studies indicate the prevalence of parents acting as carers over that provided by spouses or siblings (Ridley, Hunter & Rosengard, 2010; Wane, Larkin, Earl-Gray & Smith, 2009). This profile provides a rationale for the focus on parents who support adult children

diagnosed with a mental illness receiving compulsory treatment in a medium secure unit.

Previous research

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

The impact of mental illness on the family

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

Grief and loss are experienced as parents respond to the changes in the child they once knew and for whom the anticipated future is lost (Penzo & Harvey, 2008; Godress, Ozgul, Owen, & Foley-Evans, 2005; Ozgul, 2004; Osborne & Coyle, 2002). An interesting aspect of loss co-existing with hope is highlighted in Bland and Darlington's (2002) study into hope as a perspective for family caregivers of people with serious mental illness. They pointed out that "hope for recovery in the future is held in opposition to the grief for what has been lost to the illness" (p.64).

Although most researchers highlight the negative impact on families of having a mentally ill family member, positive aspects are also noted such as a satisfying relationship between the carer and the mentally ill relative (Bulger, Wandersman, & Goldman, 1993) and experiencing a feeling of pride in their relative's courage in overcoming adversity (Pickett, Cook, Cohler, & Solomon, 1997). This positive focus perhaps reflects the emergence of the recovery vision of mental illness on the family (Lefley, 1997).

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

Burden and measurement of burden

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

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

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

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

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

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

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

Objective measures are limited when used to quantify subjective experience, and they cannot measure the lived experience, both complex and unique to the individual. Items on checklists can be ambiguous and yield only thin descriptions of complex situations. Offering the respondent dichotomous choices cannot adequately capture the patterns in the particulars of people's lives.

Subjective burden is just that, a subjective experience rather than a discrete, universally defined concept. Thus, the difficulty with measuring "burden" is that the measuring instruments will necessarily focus on specific aspects of that experience according to the specific interest of the researcher. While this may be useful in terms of exploring the associations between narrowly defined factors, the process can ignore other potentially crucial aspects. Participants are forced into choosing between or responding to categories that may not reflect the subtleties of their experience. Subjective measures lend themselves to exploration through a qualitative methodology which allows for the richness of the individual's experience to be expressed. Wynaden et al. (2006) have noted that to date, most research on caring has focused on measuring burden and not the experience from the carer's perspective. Thus their experience remains largely hidden.

How families cope with the impact of having a relative with mental illness

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

strategies, or efforts to control the stressor demands, result in outcomes in terms of physical or psychological well-being or morbidity. Based on this model, they developed a self-report inventory around the experience of caregiving and found that well-being was associated with positive appraisal and less use of emotional coping strategies such as blaming, criticism and displacement of anger. They suggested that emotional coping follows failed efforts at practical coping. Östman and Hansson (2001) have suggested that relatives use problem solving coping strategies when they are in situations amenable to change; whereas emotion coping strategies are used in situations that are chronic and unchangeable.

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

Extending the idea that appraisals, and coping, and perceptions of the illness could be interlinked, Fortune, Smith and Garvey (2005) used a number of standardised quantitative measures to examine whether coping and appraisals were important in accounting for variance in psychological distress in relatives of patients with schizophrenia, or whether this could be determined by their perception of the illness (psychosis) alone. A list of 49 problem behaviours were generated, and participants asked to rate how much the problem bothered them (threat) and how well they felt able to

cope with the behaviour (control). Responses were dichotomised and positive responses summed to give threat and control appraisal variables. Coping was quantified by respondents indicating the extent they used the 14 coping strategies listed in the Brief COPE (Carver, 1997) from 1 (I don't usually do this at all) to 4 (I usually do this a lot). The authors found that coping through seeking emotional support, the use of religion / spirituality, acceptance, and positive reframing, were all associated with less distress. Higher threat and weaker control appraisals were also indicative of higher distress.

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

More recently, Wrosch, Amir and Miller (2011) have applied the findings of research into goal adjustment capacities to people caring for family members with mental illness. They suggested that caring for a family member with mental illness can represent a chronic stressor that renders the carer's own desired goals as unattainable. They found that both the capacity to abandon goals seen as unattainable and to re-engage with new goals, were significantly associated with how they cope with the stressful situation of caring for a family member with mental illness. Those able to disengage, blamed themselves less frequently for problems associated with caregiving, and used substances to regulate their emotions less frequently

than those who found disengagement more difficult. In addition, they experienced less caregiver burden and a higher level of subjective well-being. Although this study related to the carer's goals, it could be hypothesised that the capacity to adjust goals according to whether or not they are attainable, may also influence the carer's capacity to adjust their hopes and expectations for others, specifically the family member with a diagnosis of mental illness.

The impact of mental illness on the family over time

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

Expressed emotion (EE), "hostility, criticism, and emotional over-involvement directed from other people toward the patient, usually within a family" (Kring, Johnson, Davison & Neale, 2010) has been shown to be associated with relapse (Breitborde, Lopez & Nuechterlein, 2009). In a review of the literature on EE, Heru (2000) proposed that parental EE may be a transactional process that may originate in the patient's disruptive behaviour and is part of the adaptation to chronic illness. She suggested

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

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

Family burden for relatives of patients with mental illness appears to remain stable over time (Chadda, Singh & Ganguly, 2007; Magliano et al., 2000)

although burden decreased in families who adopted less emotion focused coping strategies, received practical support from their social network, and when the patient's social functioning improved (Parabiaghi et al., 2007; Magliano et al., 2000).

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

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

Impact of detention

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

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

Östman (2004) explored differences in burden between relatives of patients admitted for the first time and re-admitted patients in a Swedish multi-centre study. She used a semi-structured interview with 95 items developed from clinical experience, including dimensions of burden, participation in care, and attitudes towards mental health care in hospital. Respondents gave yes or no answers to facilitate a quantitative analysis. Generally there were no differences between the two groups. However, relatives of patients admitted for the first time more often viewed the psychiatric services to be of good quality and also more often initiated the admission to hospital. Östman (2004) suggested that these aspects may reflect families' hope of recovery for the ill person.

The poor treatment of carers and families by professionals

Added to the difficulties they face in having a family member with mental illness, families also describe having problems with services (Hanson, 1993; Szmukler et al., 1996). In a systemic review of the literature on burden of care, Fadden, Bebbington and Kuipers (1987) noted that despite receiving very little support from the professionals treating the patient, relatives rarely complain. More recently Johnson (2000) coded responses from a semi-structured interview of families exploring, amongst other aspects, their sense of competence in dealing with the mental health system. He found that families frequently reported feeling disregarded or dismissed as irrelevant by mental health professionals. Their opinion or knowledge was rarely sought, and they did not perceive themselves as being part of the team, even though they were expected to provide care for the patient post-discharge. He also found that although families recognised early warning signs of deterioration, this information was rarely heeded by mental health professionals. Small, Harrison and Newell (2010) used a qualitative methodology to focus on individual discourse as a way of understanding how family members experience health and social care professionals. Using information obtained from diaries completed by families over three months, together with semi-structured interview data, the authors noted the inadequate support families receive from mental health professionals and the conflict arising from families and professionals holding differing views, which in turn added to the burden of caring. Recognising the limited support available from standard mental health services, a study using Interpretative Phenomenological Analysis (Wane et al., 2009) investigated the impact of an assertive outreach team on couples caring for adult children with

psychosis. They found that involvement with an assertive outreach team led to families feeling reassured and reduced their experience of exclusion. Similarly, Chen and Greenberg (2004) found that formal support from mental health professionals through information sharing and collaborative interactions with family members was significantly associated with a positive experience of caregiving.

The impact of mental illness and forensic involvement

If the impact of having a family member with mental illness is strong, this can only be compounded by the family member committing an offence that leads to their detention in forensic services (Tsang, Pearson & Yuen, 2002). Perhaps reflecting the specialist nature of forensic services, there has been relatively little research into families and carers of patients in these services (MacInnes & Watson, 2002; Estroff, Zimmer, Lachicotte, & Benoit, 1994) and what particular stressors they may face.

In recognition that carers need support to enable them to carry out their caring role, the Government has increased its spotlight on carers in terms of policy and guidance (Department of Health 1999a, 2002, 2008a, 2008b, 2010). Guidelines for best practice in medium secure services (Health Offender partnerships, 2007) state that carers should be involved in the care process as much as possible. Researchers have reflected this focus in terms of investigating what carers and families need. In an attempt to understand the needs of relatives of patients in a high security hospital, McCann and McKeown (1995) used a structured questionnaire, together with an analysis of minutes of a relatives' support group, to explore the stress felt by relatives in maintaining contact with the detained patient.

Noting that the data provided an illuminating insight into the thoughts and feelings of relatives, the authors found that relatives felt they were not being supported, or allowed to contribute to the care of their family member. This finding is supported by MacInnes, Beer, Reynolds and Kinane (2010) who used a mixed methodology, asking carers of patients detained in medium security to rate their experiences with services on a 5-point scale, followed by an opportunity for them to expand on their answers. Their interview schedule was developed following consultation between the researchers and carer advisory groups. Carers expressed frustration at their lack of involvement while the most important support need that they highlighted was to be provided with regular and appropriate information.

A cross-sectional questionnaire survey into the provision of carer support in medium and high secure services in England and Wales (Canning, O'Reilly, Wressell, Cannon & Walker, 2009) found that although most units provided some form of support there was variation in both type and level of support offered. The questionnaire included both structured and semi-structured items, with a statistical analysis of closed questions, and a thematic analysis of open ended questions. Services identified benefits of offering such support in terms of improved relationships and communication between staff and carers. Professionals in these services identified factors which they believed may interfere with the provision of support such as carers' previous negative experiences with mental health services. Although it is helpful to gain an understanding of what healthcare professionals perceive as problematic in terms of supporting carers, this study does not purport to offer insight into how the carers themselves may think and feel. A subsequent postal survey of services provided by medium and low secure

services (Cormac, Lindon, Jones, Gedeon & Ferriter, 2010) found that many services provide a poor service for carers, some not even complying with current legislation for carers about this situation.

Some researchers have explored the use of interventions that might assist families such as relatives support groups (McCann, 1993) and family therapy (Geelan & Nickford, 1999). Geelan and Nickford (1999) noted that within medium secure services few staff were trained in this type of intervention. The professional staff from the services who completed the survey questionnaire believed that the geographical distance between families and the unit hindered the provision of the family therapy. However, Absolom, McGovern, Gooding and Tarrier (2010) found that 72% of patients (across the range of secure services; low, medium and high) had regular contact with their relatives, not the poor engagement previously identified as a barrier to the implementation of family involvement. Their analysis was based on the results obtained from structured questionnaires completed by clinical staff. The authors suggest that family interventions may be complicated because of relatives' feelings such as "anxiety, hostility, stigma, shame or guilt arising as a consequence of the forensic and mental health issues faced by the patient" (p.360). A qualitative methodology would be ideally placed to explore what relatives actually do feel. A phenomenological approach would offer insight into their lived experience.

MacInnes and Watson (2002) used in depth interviews to examine the differences between forensic and non-forensic caregivers of individuals with schizophrenia who had recently been admitted to hospital; either to a regional secure unit or an acute admission ward. Using 14 categories of burden dimensions which had been developed from a previous study

(MacInnes, 1998) the authors rated statements given by respondents during interviews according to these categories. They found that forensic caregivers were more likely than non-forensic caregivers to describe burdens relating to violence, and also "annoyance" towards services. The latter related to caregivers' anger and frustration towards services when caregivers perceived indifference, and sometimes outright hostility to their concerns. Caregivers described not being allowed to take part in discussions relating to the care and aftercare of their relative, and denied information that could directly affect them or their family because of issues of confidentiality. They felt excluded from the in-patient caregiving process and about any developments, both positive and negative relating to the patient.

Specifically looking at the experiences of parents with a son or daughter suffering from schizophrenia in a secure forensic setting in the UK, Ferriter and Huband (2003) interviewed parents of 22 patients to explore the emotional burden they experienced and their perception of the helpfulness of others in coping with that burden. They asked parents to recall experiences over a number of years rather than concentrate on current experiences that might over-emphasise the burden of recent crises. Experience of their child's illness was measured by a degree of burden scale, endorsement of items from a list of behavioural problems, and a focused life story interview which they had developed for a previous study. That the respondents raised additional difficulties to offered choices, indicates the limitations of using such discrete measures. Interview data was examined for emotional content relating to parents' responses to the behaviour of others in the context of their child's disorder. Emotional themes were

quantified, with references to stress found in all interviews, although this was not explored in detail. Other themes included loss of what might have been (91% of respondents); fear (77%); grief (73%); and confusion (50%). The authors concluded that serious offending by their child had contributed to the stress felt by parents. Further research is needed in terms of exploring the nature and quality of such experience, to offer a clearer and richer understanding. A qualitative phenomenological focus would helpfully provide further depth.

Noting the double burden carried by relatives of individuals who are both diagnosed as having schizophrenia and who show violent behaviour, Nordström et al. (2006) interviewed 14 parents of 11 adult sons, diagnosed with schizophrenia and referred for forensic psychiatric treatment in Sweden due to a violent crime. Their aim was to explore parents' experiences and emotional reactions. The patient chose which parent should be approached and three couples were interviewed together. Swedish legislation allows for diversion to forensic psychiatric treatment if the crime is committed under the influence of a severe mental disorder. Using a grounded theory approach, their analysis showed four events as crucial and common to all parents; the onset of mental disorder, the diagnosis of schizophrenia, the violent behaviour or criminality, and the referral to forensic treatment. Each event evoked strong emotional reactions. Onset of mental disorder was characterised by guilt, helplessness and anxiety, and fear of what was happening. Some mothers felt that they were not respected but viewed as “hysterical”. The diagnosis led to grief for the loss of their son’s future. Parents expressed disappointment regarding earlier psychiatric care, and blamed psychiatric services for not having

prevented the violence. It was important to them that their son was not regarded as a "criminal" but as an individual with a mental disorder. Being referred for forensic treatment was associated with relief that they could transfer their responsibility to the psychiatric unit, and hope that he would now improve and have a future.

Research has shown that when individuals who are mentally unwell become violent, family members or individuals who live in the same household as the individual with mental illness are usually the victims (Estroff, Swanson, Lachicotte, Swartz, & Bolduc, 1998; Steadman et al., 1998). Research also appears to show a link between the targets of violence from individuals with schizophrenic disorders and the severity of the violence perpetrated, with mothers being at most risk of fatal injury (Nordstrom & Kullgren, 2003).

Rationale for the present study

Studies into the experience of having a relative detained in forensic services are scarce. These studies have largely used survey approaches, or interview data, which is then quantified in terms of pre-determined categories. Other studies have obtained data from healthcare professionals rather than from families themselves. It has been argued that the quantitative emphasis in the body of family caregiving research has restricted professionals' ability to understand the many ways in which the experience of family caregiving is important to family members. I considered that a qualitative study from a phenomenological perspective would be ideally placed to explore ways that caregivers make sense of (derive meaning for) their role as a parent to a son or daughter living in a medium secure forensic setting. A better understanding of forensic carers' experiences would assist health and social

care professionals in their ability to empathise with parents in a similar situation. If parent caregivers feel understood, this in turn may improve relationships between them and mental health professionals. Finally, it is hoped that such understanding would aid in the development of services for this unique group.

Chapter 1: SYSTEMATIC REVIEW

Family involvement in care of mental health service users and relationships with mental health professionals: a structured review and synthesis of qualitative studies.

Abstract

The concept of carer involvement in mental health care planning and treatment for people with mental illness has become embedded within policy and service ideologies, and is strongly supported by carers themselves (Crawford, 2002; HM Government, 2011). However, research on carers' experiences of involvement in mental health services is limited, particularly lacking is exploration of the relationship between family members and healthcare professionals (Cree et al. 2015). The limited data that are available on family carers' interactions with healthcare professionals suggests the family feel marginalised and distanced from services (Askey, Holmshaw, Gamble, & Gray, 2008; Lyons et al. 2009; Pinfold & Corry, 2003). The objective of this review was to systematically search and synthesise qualitative literature exploring family caregivers' experiences of contact with mental health professionals. This systematic review also considered family caregivers' preferences for and experiences of, participation in the care and treatment of a family member with mental health needs, in inpatient care. Studies were eligible for inclusion in the review provided: (1) they reported primary research; (2) the study used qualitative methods of data collection and analysis; (3) data were collected from family/parent caregivers of an adult child/relative with a mental health condition, in inpatient care; (4) the intervention involved communication between family/parent caregivers and mental health professionals; (5) the study described family caregivers' experiences of contact with mental health professionals when their relative has been admitted to psychiatric care, and/or families' experiences of collaboration in care, within the inpatient setting. No search restrictions were placed on publication date, language,

or country of origin. However, only English language studies were ultimately included. A systematic search identified relevant abstracts, selected papers were reviewed, and data from seven papers were extracted. The synthesis involved elucidating and integrating common themes. Two overarching themes were identified which were deemed important and reflected the essence of what was being reported in the literature. These were: 1) the problem of confidentiality, and 2) the need of support. Carers reported difficulties in connection due to confidentiality and suppression of information; they wanted to be more actively involved in the procedures of care but experienced a lack of understanding and felt shut out. Caregivers viewed that the mental health difficulty experienced by their family member impacts on the entire family and consequently they should receive support to help them manage in this situation. Recommendations arising from the review findings sit comfortably with the recommendations of current UK government mental health strategy and professional guidance documents, regarding how services may meet the challenges of including carers of an individual with a mental health issue in the care planning process, as well as inclusion and support for family carers themselves, for their own sake.

Introduction

Background

The prevalence of mental health problems in the UK is such that at any given time, one in four adults will experience at least one or more mental disorders (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2001). Many people who experience severe mental health problems are supported by a carer, defined as "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Highet, Thompson, & McNair, 2005). The number of individuals caring for somebody with a mental health difficulty in the UK is estimated to be 1.5 million (Worthington, Rooney, & Hannan, 2013).

Formal recognition of the role and value of carers has been increased through a series of legislative measures initiated over the past 15 years (Carers and Disabled Children Act, 2000; Carers (Equal Opportunities) Act, 2004). The application of the new Mental Health Acts in England, Wales and Scotland were identified as valuable opportunities for services to make real changes to care planning involvement, and to ensure that wherever possible carers are involved in developing service users' care plans (Katona, 2004). These initiatives are additionally supported by other government policies, including the National Carers Strategy (Department of Health, 1999, 2004; Welsh Assembly Government, 2005, 2008). Professional guidance and good practice documents have been issued that provide advice to mental health professionals on promoting carer involvement (National Institute for Clinical Excellence, 2014; Royal College of Psychiatrists, 2010; Triangle of care, 2010, 2013). In the forensic context, guidelines for best practice in medium

secure services state that carers should be involved in the care process as much as possible (Health Offender Partnerships, 2007). As a result, the concept of carer involvement in the mental health care planning process has become embedded within policy and service ideologies, and is strongly supported by carers themselves (Crawford, 2002; HM Government, 2011).

'Family involvement' in mental health services can take different forms, depending on the level of need and availability of services (Eassom, Giacco, Dirik & Priebe, 2014). Generally, it can be conceived on a spectrum from more basic functions to specialised interventions, the minimal level including the provision of general information on the mental health service and assessments. On a more complex and specialised level, services can offer families psycho-education, consultation, family interventions and therapies (Mottaghipour & Bickerton, 2005).

Research has shown that the existence of a collaborative relationship between mental health professionals and family caregivers, can greatly benefit the individual with mental illness. In a review by Dixon, Adams, and Lucksted (2000), which considered implementation of family interventions for people with schizophrenia, the authors reported that family inclusion significantly improved the ill family member's treatment adherence, reduced relapse rates, and increased family caregivers' well-being and coping strategies.

In the U.K, the National Institute for Clinical Excellence (NICE) Schizophrenia guidelines, originally published in 2002, recommended family interventions should be offered to 100% of individuals with schizophrenia who have experienced a recent relapse. The revised and updated review of

the guidelines (2014) confirms this, and further recommends that families are offered intervention and engaged during the acute phase of illness, or as a method of promoting recovery for those with persisting symptoms. The NICE Guidelines for bipolar disorder (2014) similarly recommend focused family intervention for people with bipolar disorder in regular contact with their families, stating it should include psycho-education about the disorder, ways to improve communication and problem solving.

Despite the vast evidence base for family involvement (British Psychological Society, 2009; Lucksted, McFarlane & Downing, 2012; Marshall & Rathbone, 2011; Murray-Swank & Dixon, 2004; Pfammatter, Junghan, & Brenner, 2006; Pharoah et al., 2010; Pilling et al., 2002; Pitschel-Walz et al., 2004) findings of a systematic review by Eassom, Giacco, Dirik and Priebe (2014) on implementing family involvement in the treatment of patients with psychosis, suggest that family involvement is often not implemented in routine mental healthcare.

In a survey conducted by Kaas, Lee, and Peitzman (2003), mental health professionals stated that there were a number of barriers that contributed to their lack of collaboration with families. These barriers were lack of time, lack of expertise in dealing with families, and lack of support given by service agencies to work with families. According to family caregivers, the major problems they experienced were too brief and infrequent contacts with professionals (Ferriter & Huband, 2003). In addition, confidentiality when working with the family *and* the individual with mental illness was found to be a serious dilemma for mental health professionals (Davis, 2002; Kaas et al., 2003; Leggatt, 1993; Rapaport et al., 2006). This conflict

between the patient's right to confidentiality and the family's right to information and confidentiality (Zipple, Langle, Spaniol, & Fisher, 1990) has caused much frustration and stress for the family caregivers and seems to have negatively impacted their relationship with mental health professionals (Marshall & Solomon, 2000; Peart, 1996). It is further suggested that there is a lack of understanding from some professionals of the caring role which may result in a lack of empathy (Rapaport et al., 2006). Carers have identified that input from professionals is mainly focused on information gathering and for the primary benefit of the professionals (Johnson, Needle, Bindman, & Thornicroft, 2008). Jones (2004) further argues that relatives of someone with a severe mental illness experience complex emotions of guilt and loss. When not involved by professionals, carers describe feelings of anxiety, depression, isolation, fear, anger and resentment towards the person with mental health problems (Gray, Robinson, Seddon, & Roberts, 2008; Wooff, Schneider, Carpenter, & Brandon, 2003).

Existing systematic reviews

Rowe (2011) conducted a systematic review which aimed to find out what professionals expected of family carers and what family carers expected of themselves in respect of their relative with a mental health difficulty. This review covered research carried out in UK healthcare settings, between the years 2005 and 2010, with six electronic databases being searched and 13 quality assessed studies that met the study inclusion criteria. The findings, search strategy and analysis had some success in addressing the aims of the review. Insight was gained into what mental health practitioners expected family carers to do, and what family carers expected themselves to do. There were limitations though, to the extent to which the review

answered what was expected of family carers because this was not the question that any of the studies tried to answer. Restricting the search to one geographical area meant that international data were excluded, thus narrowing the number of potentially relevant research articles that might have been useful in informing and developing collaborative-orientated local practice.

A more recent review which does provide some information on collaboration between professionals and relatives when the family member with a mental health problem is an inpatient, was conducted by Eassom et al. (2014). The review specifically focused on barriers, problems and facilitating factors for the implementation of family involvement in the treatment of patients with psychosis. An electronic search was carried out in seven databases, with a total of 43 studies that met the study inclusion criteria. Results indicated that facilitating the training and ongoing supervision needs of staff are necessary, but not sufficient conditions for the consistent involvement of families. Furthermore, the review authors identified that organisational cultures and paradigms can work to limit family involvement. Another finding emerged of families sometimes being reluctant to engage, linked to existing individual and family problems. Eassom et al. (2014) considered the review to be original in covering a wide range of family involvement practices, highlighting common barriers, problems and facilitating factors. However, the review authors acknowledged that the work may be conceptually limited, as the extant research has focused on perspectives of staff involved in family work and few studies are available on the views of the family in their own right.

Aims and objectives

The objective of this review was to synthesise the existing qualitative literature in this circumscribed area, and provide a more comprehensive understanding of the ways family caregivers' experience contact with mental health professionals. This systematic review also considers family caregivers' preferences for and experiences of, participation in the care and treatment of a family member with mental health needs, in inpatient care.

It aimed to address the following questions:

1. What are family/parent caregivers' experiences of contact with mental health professionals?
2. What are family/parent caregivers' experiences of involvement in care, when their family member with a mental health condition is hospitalised?
3. What are family/parent caregivers' perceived needs and wants regards collaboration in treatment, when their family member with a mental health condition is receiving in-patient care?

Method

Search strategy: sources of literature

Different sources of published and unpublished research literature were searched to locate relevant reports. The databases selected for this systematic review were: PsycINFO (1806 to March week 3, completed on 20th March 2016); Medline (1948 to March week 3, completed on 20th March 2016), both accessed via OVID SP; the Cumulative Index to Nursing and Allied Health Literature (CINAHL) (from 1981 to March week 3, completed on 20th March 2016), accessed via EBSCO; and Applied Social Sciences Index and Abstracts (ASSIA) (from 1988 to March week 3, completed on 20th March 2016), accessed via Proquest. Grey literature was identified via Google Scholar, DART Europe, EThOS, and OpenGrey, all searched on 12th March 2016. Different search strategies were designed according to the specific characteristics of each database. Reference lists from the existing systematic reviews by Eassom et al. (2014) and Rowe (2011) were also read for potential papers that might answer the review questions. Titles in past issues of *International Journal of Mental Health Nursing* and *Journal of Psychiatric and Mental Health Nursing*, up to March 2016 were hand searched. The two nursing journals identified were chosen because in a scoping search they seemed to appear more in my search results than others, which appeared to indicate higher relevance to the review topic.

Search strategy: search terms

The following is a *guide* to the search terms that were used in all databases (modified to meet the requirements of each database due to field differences). A complete list of the terms included for each database search is provided in appendix 1.

"famil*" OR "caregiver*" OR "father*" OR "mother*" OR "parent*"

AND

"adult child*" OR "daughter*" OR "son*" OR "relative"

AND

"mental disorders" OR "mental health" OR "mentally ill persons" OR "inpatient" OR "psychiatric hospital"

AND

"mental health professional*" OR "nurse*" OR "clinician*" OR "psychiatrist*" OR "psychologist*" OR "social worker"

AND

"collaboration" OR "communication" OR "cooperat*" OR "interact*" OR "involvement" OR "participat*" OR "relationship*"

AND

"experience" OR "feel*" OR "perception" OR "perspective" OR "view" OR "attitudes" OR "emotions"

In the interests of exhaustiveness, MeSH terms were combined with a multi-purpose keyword term to pick up results that are not indexed with the subject heading but where the term appears somewhere in the searchable fields of a record. Having grouped together similar terms, the OR operator was used to combine them into a set. The same approach was taken for each of the concepts in the PICO. All sets were tied together using the AND operator. This created a foundation from which studies on family caregivers'

involvement in care planning and interactions with mental health professionals, were manually screened and selected. The search term *qualitative* was not used as many electronic databases have only recently begun to index qualitative research with a specific subject heading and it was felt that in looking only at results where this term appears along with the other search terms, it may potentially exclude relevant studies.

Study selection

Studies were eligible for inclusion in the review provided: (1) they reported primary research; (2) the study used qualitative methods of data collection and analysis, i.e. either a stand-alone study or a discrete part of a larger mixed-method study; (3) data were collected from family/parent caregivers of an adult child/ relative with a mental health condition, in inpatient care; (4) the intervention involved communication between family/parent caregivers and mental health professionals - these communications were for the purposes of discussing and/or addressing the ill family member's mental health needs; (5) the study described caregivers' experiences of contact with mental health professionals when their relative has been admitted to psychiatric care, and/or families' experiences of collaboration in care, within the inpatient setting. No search restrictions were placed on publication date, language, or country of origin. However, only English language studies were ultimately included.

Articles were excluded if: (1) they DID NOT report primary research, i.e. they were review articles (systematic, narrative), opinion papers etc; (2) they DID NOT include qualitative methods of data collection & analysis, i.e. family members' experiences were collected and analysed *only* using

quantitative methods; (3) the adult family member with mental health needs was living in the community, therefore was not an inpatient receiving hospital care; (4) the respondents were family/parent caregivers looking after children and adolescents with mental health difficulties, because the population of interest in this review was family caregivers of *adult* children with a mental health condition. The above criteria are presented in Table 1.

Qualitative studies are particularly suitable for exploring the attitudes, beliefs and ideas informing how an issue is perceived and can capture the lived experience of the respondents (O'Leary, 2004). It was considered appropriate that any study that used qualitative methods of data collection and analysis for example, either a stand-alone study or a discrete part of a larger mixed-methods study, would be suitable for addressing the review questions and would therefore be considered for inclusion in the review.

Studies were excluded if they *only* used quantitative methods of data collection and analysis because the author felt such data would not be amenable to answer the review questions on family caregivers' experiences of involvement in care planning, and interactions with mental health professionals in inpatient care settings. However, using qualitative methods of data collection and analysis would enable the reviewer to gain access to this type of knowledge, given the focus in qualitative research on an individual's subjective perception and explanation of their lived experience.

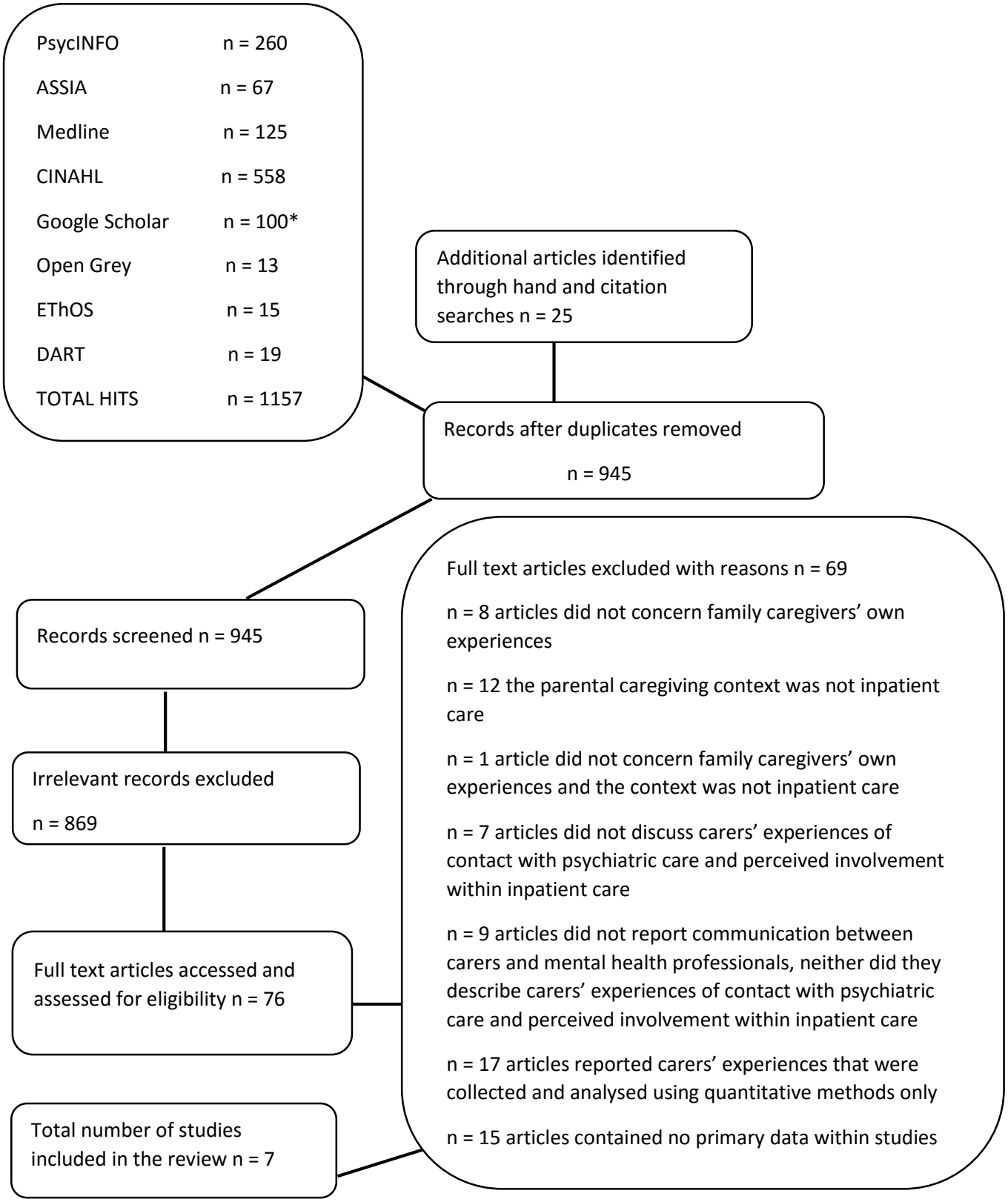
Papers were manually examined for their suitability for inclusion based on their title or abstract. Irrelevant papers were removed. Full-text versions of the remaining studies were obtained and compared against inclusion and exclusion criteria developed to support answering the review questions.

Those that met the inclusion criteria were selected for further quality assessment. The inclusion and exclusion of studies was carried out by one reviewer, using a predefined form (see appendix 2). It was double checked by this individual to minimise errors. Details of the studies that were included and those studies that were excluded, along with reasons for their exclusion are described in Appendix 3. A flowchart to illustrate the study selection process is provided in Figure 1.

Table 1. Inclusion and Exclusion criteria

Parameters	Inclusion	Exclusion
Population	Family/ parent caregivers of adult children with a mental health condition	Family/ Parent caregivers of children and adolescents with mental health difficulties
Intervention	Any communication, a relationship or contact between family/ parent caregivers and mental health professionals providing treatment to their family member with a mental health difficulty	
Context	The adult child/relative with mental illness is living in an inpatient care setting.	The adult child/relative with mental illness is living in a community setting (this may or may not be the same household as the family caregiver supporting them).
Outcome	Family/ parent caregiver's personal perspective of, or subjective view regarding interactions with mental health professionals, and/or: families' experiences of collaboration in care, within the inpatient setting.	
Article type	Primary research	Narrative and Systematic reviews Letters Commentaries Discussion papers Editorials
Study type	Any study that adopted qualitative methods of data collection and data analysis, i.e. either a stand-alone study or a discrete part of a larger mixed-methods study.	Any study which uses *only* quantitative methods of data collection and analysis
Language	No limitations	
Country of origin	No limitations	
Time frame	No limitations	

Figure 1. Flow chart summarising search strategy



*the first 100 records returned by the search engine Google Scholar were reviewed. The actual number of hits was 174000

Quality Assessment

The quality of each study was assessed using a tool developed from the amalgamation of published quality checklists (see appendix 4). There were two screening questions which acted as a filter, and eight quality criteria, centred upon areas including rigour, credibility, and relevance of methodology and findings. The quality criteria were applied by the sole researcher to each of the 7 studies. In order to make transparent the application of the quality criteria, an appraisal system- created by Downe, Finlayson, Walsh and Lavender (2009) based on the work by Lincoln and Guba (1985) was used. The quality appraisal stage therefore involved: assessing each study according to the criteria listed in appendix 4; a positive rating indicates a consideration by the original authors of this point within the quality assessment checklist, whereas a negative rating indicates a lack of evidence that this point has been considered by the researchers. A final overall mark ranging from A-D (table 2) was then awarded to each study based on these quality assessment criteria. Studies assessed as grade A, B and C were used in the final synthesis. D graded studies were rejected. The resulting grades of the 7 studies were A = 3 B = 4 C = 0 D = 0. A summary of the outcome of this process of quality appraisal is presented in Table 3.

Table 2. Grading of study quality

A	No, or few flaws. The study credibility, transferability, dependability and confirmability is high.
B	Some flaws, unlikely to affect the credibility, transferability, dependability and/or confirmability of the study.
C	Some flaws that may affect the credibility, transferability, dependability and/or confirmability of the study.
D	Significant flaws that are very likely to affect the credibility, transferability, dependability and/or confirmability of the study.

Table 3. Quality appraisal process applied to the included studies

		Evavold et al. (2003) Grade A	Goodwin & Happell (2007) Grade B	Cree et al. (2015) Grade A	Sjoblom et al. (2008) Grade B	Wilkinson & McAndrew (2008) Grade A	Wynaden & Orb (2005) Grade A	Van de Bovenkamp & Trappenburg (2010) Grade B
Screening Questions	Clear statement of research aims	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Qualitative methodology appropriate	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Detailed Questions	Rationale provided in relation to how researcher decided on which methods to use	√	√	√	√	√	√	√
	Discussion around recruitment strategy	√	√	√	√	√	√	√
	Data collected in a way that addressed the research issue	√	√	√	√	√	√	√
	Ethical issues taken into consideration	√	√	√	√	√	√	√
	Relationship between researcher and participants considered	√	-	√	-	-	√	-
	Data sufficiently rigorous: reflexivity considerations, triangulation	√	-	√	-	√	√	-
	Clear statement of findings	√	√	√	√	√	√	√
	Study findings contribute to theory development and future practice/research. Valuable Research	√	√	√	√	√	√	√

Data extraction

Further relevant data was extracted from each quality assessed study using a predefined pro-forma (British Psychological Society & Gaskell, 2007) to ensure the same data was extracted. The form allowed for both general information and more specific details of the study to be recorded. A copy of the NICE data extraction form used can be found in Appendix 5.

Results

Description of studies

The electronic search yielded 1157 hits, and a further 25 articles were identified through hand searches of journals as well as reference lists of two existing systematic reviews. Thus, the total number of publications and citations identified was 1182. Of these, 237 were duplicate references, and were excluded leaving 945 references. All titles and/or abstracts of the 945 papers were read. 869 were found to be irrelevant to the subject area and excluded at this point. 76 full text articles were accessed and examined more closely using PICO criteria. 69 articles were excluded after their full text versions had been analysed. The reasons for exclusion included: articles did not concern the lived experience of family/ parent caregivers of adult children with a mental health condition n= 8; articles did not report the perspective of carers of adult children/relatives with mental illness who were admitted to inpatient care n= 12; the article did not concern family caregivers' own experiences and the context was not inpatient care n = 1; articles provided no information on family/ parent caregivers' subjective views of their interactions with mental health professionals, and/or families' experiences of collaboration in the inpatient setting n= 7; there was no report of communication between family/parent caregivers and mental health professionals, and neither were there accounts of carers' experiences of contact with psychiatric care and carers' perceived involvement within inpatient care n= 9; Family members' experiences were collected and analysed using quantitative methods only n= 17; articles did not include primary data n = 15. This left 7 papers that were taken forward for quality assessment. All 7 studies met the quality requirements. A grade ranging

from A-D was given to each paper, with 3 studies classified as grade 'A' and 4 studies classified as grade 'B'. The main characteristics of the 7 included studies are noted in Table 4.

Characteristics of included studies

The review did not identify any papers meeting the inclusion criteria that were published before 2003, with the most recent paper being published in 2015. The journal outlet for the majority of published papers was in the nursing field (n = 5). One unpublished thesis was included in the review (study 1). The 7 papers included in the qualitative synthesis represent findings from 5 countries – Australia, America, The Netherlands, Sweden, and the United Kingdom. The included studies used either focus groups and/or in-depth semi structured interviews to gather data from a total of 176 family/parent caregiver members. The smallest study had 4 subjects (study 5) while the largest had 58 participants (study 2). Across all studies, the leading perspective was that of parents who were caring for a son or daughter with a mental illness in inpatient care, and within this carer group, more experiences came from mothers than fathers. The ages of the carer participants (where stated) ranged from 35 – 80 years. The length of time caring varied from 1 to 33 years. The mental health condition for which family members were receiving inpatient care and treatment included schizophrenia, bipolar disorder and psychosis. The majority aim of the included studies was exploration of the lived experience of informal carers and interactions with healthcare professionals providing support to their relative with a mental health condition.

Table 4. Characteristics of included studies

Authors & Number of Study	*Year*	*Country*	*Discipline*	*Perspective & age range of carers*	*No of participants*	*Family member's mental health diagnosis*	*Data collection*	*Methodology*	*Analysis*	*Experiences explored*
Evavold *(Study 1)* Grade: A	2003	USA	Social Work	Parents 35-80 years	16	Schizophrenia	Semi-structured interviews	Exploratory	Holloway's (1997) strategy	Family members' views of experiences with mental health professionals
Goodwin & Happell *(study 2)* Grade: B	2007	Australia	Nursing	Parents, spouses. age range not stated	58	Not explicitly stated	Focus groups	Exploratory	Content Analysis	Carers' experiences and understandings of participation in mental health care
Cree et al. *(study 3)* Grade: A	2015	United Kingdom	Nursing	Parents age range not stated	37	Not explicitly stated	Semi-structured interviews and focus groups	Qualitative	Framework Analysis	Carers' experiences of the care planning process

Sjöblom et al. *(study 4)* Grade: B	2008	Sweden	Nursing	Parents, siblings. age range not stated	16	Not explicitly stated	Focus groups	Qualitative	Content Analysis	Family members' experiences of contact with psychiatric care
Wilkinson & McAndrew *(study 5)* Grade: B	2008	United Kingdom	Nursing	Parents, spouses. age range not stated	4	Schizophrenia, depression, Bipolar disorder	Semi-structured interviews	Phenomenology	Van Manen (1990)	Informal carers' experiences when their relative is admitted to an acute inpatient setting
Wynaden & Orb *(study 6)* Grade: A	2005	Australia	Nursing	Parents age range not stated	27	Schizophrenia, Bipolar disorder, obsessive compulsive disorder	Semi-structured interviews	Grounded Theory	Glaser & Straus (1978)	Exploration of how patient confidentiality issues impact on carers
Van de Bovenkamp & Trappenburg *(study 7)* Grade: B	2010	The Netherlands	Counselling	Parents, siblings, spouses. age range not stated	18	Schizophrenia, Bipolar disorder, Psychosis	Semi-structured interviews, observations of care practice and meetings	Multi-method	Content Analysis	relationship between family and mental health staff to learn about the support available

Integrating/synthesising qualitative research

A range of methods for synthesising qualitative research have been identified and applied; there are no standard or agreed methods for conducting syntheses of qualitative research (Barnett-Page & Thomas, 2009). Thematic analysis, meta-ethnography and realist review are three of a number of examples of qualitative synthesis methodologies, which are well utilised within the general literature and which provide good representation of the types of variation in qualitative synthesis methodology (Bearman & Dawson, 2013).

Thematic analysis is an umbrella term rather than a description of a process grounded in a particular formal protocol. In general, thematic analysis refers to the various processes of reading texts and refining the findings into key 'themes' (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005). These themes represent ways of understanding the combined meaning of the text. They can be derived by such informal means as reading the texts and describing key messages, or more rigorously by coding a meaning against a specific section of text and then iteratively grouping open codes into themes. In addition to being a qualitative synthesis methodology, thematic analysis is a commonly used approach to analysing qualitative data of all descriptions (Bearman & Dawson, 2013).

Realist review methodology was introduced by Pawson, Greenhalgh, Harvey and Walshe (2005). In this approach, explanatory theories are used to provide a framework for the phenomenon under review. The qualitative synthesis seeks to shed light on these frameworks and does so by trying to understand any or all of the following components: *what* it is about this kind

of intervention that works, for *whom*, in what *circumstances*, in what *respects* and *why* (Pawson et al., 2005). The realist methodology provides a way of conducting reviews that aim to 'identify and explain the interaction between context, mechanism and outcome' (Wong, Greenhalgh & Pawson, 2010).

Meta-ethnography (Noblit & Hare, 1988) is perhaps the most well developed, and frequently used, method of synthesising qualitative research findings (Beck, 2002; Britten et al., 2002; Campbell et al., 2003; Nelson, 2002; Paterson et al., 1998). This method involves 7 phases that overlap and repeat throughout the synthesis. Phases include the following: identifying an interest that may be informed by qualitative data; deciding what data are relevant through an exhaustive literature review; reading the studies in detail; determining how the studies relate to each other; translating the studies into each other, so major concepts are derived from each study and compared to those from other studies to extract overarching themes; synthesising the translations, making the whole into something greater than the sum of its parts; and finally, expressing the synthesis in the language of the audience (see appendix 6).

The common link between these different methods to combine/synthesise qualitative research findings is that they all attempt, at varying levels, to draw out and integrate findings across studies in ways that generate new insights and understandings (McDermott, Graham & Hamilton, 2004).

One of the most problematic aspects of qualitative synthesis methodology is the tension between developing practical and communicable methods

that synthesise qualitative findings and, simultaneously maintaining the integrity of individual studies (McDermott, Graham & Hamilton, 2004).

Part of the appeal of meta-ethnography to qualitative researchers is its potential as a method which can preserve the interpretive properties of primary data. Also, it is one of the few methods to lay out explicit guidelines for conducting a synthesis (see also Paterson et al., 2001). Furthermore, Britten et al. (2002) and Campbell et al. (2003) have both conducted evaluations of meta-ethnography and claim to have succeeded by using this method, in producing middle-range theories with greater explanatory power than could be achieved in a narrative literature review.

One problem with meta-ethnography is that it is envisaged as a method for synthesising ethnographic qualitative research, that is, qualitative research which uses a similar theoretical/conceptual framework. The issue of whether it is suitable for synthesising studies from a wider range of perspectives and methodologies remains unresolved (Campbell et al., 2003) and intensely debated (Dixon-Woods et al., 2003). Jenson and Rodgers (2001) argue that meta-ethnography should only be used to synthesise studies within a single paradigm. However, Campbell et al. (2003) has demonstrated that it is possible to utilise the method for studies from various qualitative traditions (see also Sandelowski et al., 1997).

It was for these reasons outlined, that meta-ethnography was selected as an appropriate method to collect and interpret qualitative accounts of family caregivers' experiences of contact with mental health professionals, and family caregivers' perceptions of involvement in care of mental health service users.

Validity/reliability

Though the systematic review attempts to follow the same rigorous structure as the traditional quantitative analysis, the difficulty in doing so arises from the near impossibility in replication of the search process and synthesising (Dixon-Woods et al., 2006). Therefore, reliability is not entirely applicable to the qualitative studies as it employs a more 'organic, creative and interpretive approach to conducting review of complex literature' (p.39)

The entire analysis was completed by one reviewer, although attempts to be transparent and critical were achieved by presenting tables in the text and within the appendices on omitted papers, included papers, the qualitative synthesis process, and summary of findings.

Synthesis

Through the process of synthesising and translating the study findings (see Appendix 6), two overarching themes were identified which were deemed important and reflected the essence of what was being reported in the literature. These were: 1) the problem of confidentiality and 2) the need of support. Carers reported that client confidentiality impacted on their caregiving role, that they wanted to be more actively involved in the procedures of care but experienced a lack of understanding, and felt shut out. Participants viewed that the mental health difficulty experienced by their family member has an impact on the entire family and consequently they should receive support to help them manage in this situation. Thus the LOA for this synthesis is that there is an uneasy relationship between health

care professionals and family members, who are considered more as outsiders. Table 5 lists the studies that discussed each theme.

Table 5. Themes identified in each study

	Study number						
Themes	1	2	3	4	5	6	7
The problem of confidentiality:							
Not being informed about the condition	yes	Yes	yes	-	yes	yes	yes
Influence on well-being	yes	yes	yes	yes	yes	yes	yes
Impact on caregiving ability	yes	yes	yes	-	-	yes	yes
Strained relationships	yes	-	yes	yes	-	yes	yes
Purpose in knowing	yes	-	-	yes	-	yes	yes
The need of support:							
Lack of material and professional resources	yes	Yes	yes	yes	-	-	-
Accessing information and education	yes	Yes	-	yes	yes	yes	-
Compassionate approach	yes	Yes	yes	yes	yes	-	yes
Acknowledgement of emotional needs	yes	Yes	-	-	yes	-	yes
The carer as expert	yes	Yes	-	yes	yes	-	-

Summary of themes and sub-themes

1. The problem of confidentiality

The majority of the included studies highlighted that part of what frustrated the family carers most was the health professionals' attitude to confidentiality; which several of them considered far too rigid and one-sided, bordering on suppression of information, where even general information on the condition and treatment was withheld.

Not being informed about the condition

(n=6 study numbers: 1, 2, 3, 5, 6, 7)

Carers were particularly concerned that they were not provided with information about the family member's mental health condition and treatment, and about how they could be more effective as carers. For example, one carer said: *"You are supposed to be actively involved in the treatment, part of the treatment team but you stumble through and pick up the pieces because they [health professionals] don't involve you at all."* (study 6)

Another carer in the same study reported: *"When [daughter] is in hospital the doctors don't like to talk to us [parents]. They say, 'confidentiality is a big thing'. When [daughter] was first in hospital it was fine. But now, unless she agrees, unless she can be there in the interview, and unless this and unless that, we don't find out anything. We keep arguing that it is wrong. We have to watch out for her so why shouldn't we find out about things. We just think it is wrong to have that level of confidentiality."* (study 6)

A carer in a separate study put it this way: *"Nobody ever spoke to me about the illness and nobody ever explained anything to me. I didn't understand what was going on*." (study 5)

Another carer said: *"So it was like huge barricades up around this information. So… that in itself as you can imagine, was intensely upsetting, and infuriating. But it's more that it symbolises this idea that as the carer you're nobody."* (study 3)

Influence on well-being

(n=7 study numbers: 1, 2, 3, 4, 5, 6, 7)

Participants explained that patient confidentiality impacted on their level of well-being because health professionals were unable to differentiate between information that could be shared with them and information that should remain confidential. Study 6 stated that when confusion occurred, the health professional typically opted to withhold all information about the mentally ill family member from the carer. The fact that information was not shared with parent/family carers left them with feelings of powerlessness and detached from the care of their relative. One carer described: *"If I rang the ward, I was told that his care can't be discussed over the phone because of confidentiality… they said I could be anyone ringing up… but I didn't want to know all the details, I didn't want to know what he [patient] discussed in confidence. I just wanted to know that he was safe. I needed peace of mind because I just felt so far away from everything."* (study 5)

Family/parent caregivers expressed an acceptance that confidentiality has to be adhered to, but nevertheless regretted the lack of understanding and

compassion for how painful such a restriction could be for them. *"I was told that 'your son is an adult' and I wasn't privileged to any information at all about medication or anything to do with him. Even though I rang and asked and wanted to be involved, I was just denied involvement. They were very selective about what they told me. When they chose to tell me something it was for their benefit, it was not for mine. It did nothing to help my son or myself."* (study 2)

This was an emotive subject for many carers, and it could often reinforce self-blame that they may have somehow contributed to the individual family member's mental ill-health. *"I think there's still issues around that of… are parents, for example, to blame for the mental illness? Are they a hindrance to the person getting better? There's all sorts of things like that… they're not far under the surface, those kind of things. And certainly when I talk to carers…whose children have been admitted and have chronic, you know, severe episodes and so on… they feel just immediately excluded like, it's nothing to do with them or… almost made to feel they're the enemy."* (study 3)

A mother in study 5 expressed similar views: *"As soon as he was admitted to the ward I became a nobody, an outsider, but I'm not an outsider, I'm his mother!"* (study 5)

Impact on caregiving ability
(n=5 study numbers: 1, 2, 3, 6, 7)

A mother in study 1 explained how frustrating she found it not being communicated with or involved as part of the treatment team: *"I have not been informed of my daughter's progress or what is going on. I need to*

know if progress is made, and what she is working on this week, and what they are trying to accomplish with her. Have they changed the medicines this week? What should I be looking for as far as behavioural changes? I have not been informed of any of this. How can I help my daughter if I don't know what is going on?" (study 1)

One mother of a son with schizophrenia reported she had been excluded from her son's care and advised of the far-reaching consequences that had had: *"They said that it [involving me] would not be good for his treatment. The consequence was they started working with too little information, which resulted in a faulty diagnosis. Then he attempted suicide for a second time and a third."* (study 7)

Another carer in study 3 said as follows: *"I couldn't get people to tell me… because of confidentiality, you see, and confidentiality is right. I want confidentiality for my son, I want respect and I want people to listen to him, but also I need to be listened to."* (study 3)

Similarly, a carer in study 2 said: *"You know it would certainly help if there was a greater flow of communication. I understand the confidentiality issues, but that really hinders I think, the family member's role with the person with mental illness."* (study 2)

"Furthermore, a carer in study 6 stated: *"This holy grail, this confidentiality thing… I just wanted to feel that I was doing things along the same lines, things that were advisable or helpful. I just want some guidance."* (study 6)

Strained relationships

(n=5 study numbers: 1, 3, 5, 6, 7)

In a number of studies carers reported difficult situations had arisen which impacted negatively on the adult-child – family carer relationship. This occurred when parents' felt health professionals had breached their own confidentiality, by telling the inpatient family member things they had specifically told them not to. These different standards of confidentiality for professionals would appear to reflect a relegation of the families' role and prioritisation of the ill relative within services. *"There have been times when, you know, I've said things about my son because I felt he was becoming unwell, but I didn't want the nurse to say to my son… that I'd told him. So… the nurse went and told my son and that made my son very cross and so we had to build bridges again."* (study 3)

A carer in study 6 explained: *"This one-way process of patient confidentiality impacts not only on our ability to care but also on our relationship with our ill family member."* (study 6)

Participants in study 5 felt that one way to ameliorate the situation would be for professionals to engage carers in an open and honest dialogue, in which they explained in a meaningful way what confidentiality actually meant in their individual situation, but that there should be a consistent approach from all professionals and this would require relevant and up-to-date training. *"I'm really concerned that people should have training on that, you know, confidentiality, that everybody knows what they're saying, because if one person says one thing, another person says another, then the poor, well the carer in particular is...on a hiding to nothing."* (study 5)

Purpose in knowing

(n=4 study numbers: 1, 4, 6, 7)

When carers requested information, it was to facilitate a better understanding of the family member's illness and treatment interventions, and strategies that could be used to optimize the family member's recovery: *"We really want to know what are the signs to look out for, which we probably know already. We want to know which ones to really look out for, rather than ones that are silly to watch out for. We want to know where we really ought to go [how to help their daughter] and that sort of thing."* (study 6)

Another parent carer in study 1 reported: *"I grab pieces of information where I can get them. It would be nice to get reports from them [mental health professionals] to know what she is doing well and what the plan is for her. That would relieve a lot of our stress, but we don't get any kind of connection from any of them [mental health professionals] to know if things are moving forward or if she [daughter] is doing better. For now, I just use my instincts to know if things are getting better or not."* (study 1)

In study 4 parents' desire for provision of information appeared connected to alleviating subjective burden, for example one mother in the study said: *"If we are confident about the care our loved one is receiving, we feel that our devotion is not needed so much. When the caring procedure functions, you feel secure."* (study 4)

2. The need of support

Information exchange and consultation about the mentally ill family member was reported to be important for the parent/family caregiver to enable them to be effective in their carer role. In addition to this, family members in the included studies expressed a great need for guidance and support to be able to cope with the presenting challenging circumstances. Participants across the studies regarded the hospitalisation of a family member as an occurrence involving the entire family and consequently the carers should receive information and help from professionals, to enable parents to cope with feelings related to having a son/daughter with a serious mental illness admitted to inpatient care.

Lack of material and professional resources
(n=4 study numbers: 1, 2, 3, 4)

Most respondents reported that they did not receive any support at all. A father in study 1 described a desperate situation in which he and his wife were looking for answers and getting no feedback or support from mental health professionals: The father stated: *"We were excluded from the system for about eight years. We were out there floundering around trying to get help, pleading for help. Both of us went to the doctor and pleaded for help and asked what can we do? The doctors didn't mention anything about support groups or any other resources in the community or point us in any direction- our pleas were basically ignored."* (study 1)

Some participants were very specific about the need for referral to carer support groups: *"What we need is a positive to come out of it…. Referrals*

to [be made to] a support group; for people to know that you're there." (study 2)

There were attitudes among carers that with the appropriate organisational support, family caregivers would be able to contribute meaningfully and appropriately to care planning decisions. One suggestion for this support was that in times of conflict between patients and their family carers, an independent and qualified mediator could make assessments about carer involvement and advise accordingly. *"I think it's a really difficult area... that understandably there's confidentiality and so on. But I also think the carers… should have a voice. I think it should be assessed by somebody who's really qualified to assess it and, weigh the balance up of what the carer's saying, what the service user needs and is saying, and make a judgement that way. But often carers are not listened to at all and are completely left out of the equation."* (study 3)

Accessing information and education

(n=5 study numbers: 1, 2, 4, 5, 6)

Foremost among the suggestions for improvement was the need for good access to information and education about the symptoms, care and treatment of mental health conditions. Many carers believed that the sharing of this type of information in a timely and appropriate way would improve the working relationship between family carers and health professionals. The following poignant statement taken from study 2 underlines this: *"Family education, early intervention. Information that's available- not three days before your son dies. Communication, and the carer being listened to."* (study 2)

Family carers in some of the studies reported that even when they actively sought out information from the professionals they rarely received it in sufficient quality or quantity. *"We have pretty much done it all through the internet and through friends and family members, because the information wasn't provided to us… I wish Dr [name] would just see me and not release any of my daughter's information, but coach me on how to live with it. Maybe he could teach me not to worry so much."* (study 1)

The following excerpt from a carer in study 6 indicates that this mother had a poor level of knowledge and understanding about her son's schizophrenia, and it would appear that she was not provided with information and education about her son's mental health condition, despite the article noting that the individual had been caring for him for over four years: *"I have read as much as I can on it [schizophrenia]. I don't fully understand it. I know it is a chemical imbalance in the brain. I know that his symptoms they are never able to complete anything. Is that right? I hope one day he is going to get better."* (study 6)

Compassionate approach
(n=6 study numbers: 1, 2, 3, 4, 5, 7)

Carers made the point that there needed to be improvement in basic communication and the fostering of caring attitudes. A brother of a sister who had been an inpatient for 40 years said as follows: *"When I visit my sister and she doesn't want to see me, then I like a nurse who is there for me and says: 'Hey, yesterday she was doing a lot better' or whatever. I want someone in the hospital who will call me every six months, if necessary 'How are you doing?' That's 5 or 10 minutes work."* (study 7)

Parents in study 4 reported being met with negative attitudes from professionals, which were not expressed directly but could be felt through a lack of empathy and understanding, for example: *"I wanted to go in and see the doctor with her (daughter), but he waved his hand and sent me away."* (study 4)

If carers had been involved in the care planning process, there were structural barriers to participation such as not being invited to attend meetings or only being told about meetings once they had happened: *"Sometimes, I wasn't told about the reviews until they'd actually happened… and that was really annoying, because there's things obviously I'd seen in my son, having visited him every day, and I could speak from more knowledge than the professionals could."* (study 3)

Study 4 and Study 5 in particular described the powerlessness of families, and that while the carer participants were unhappy with the situation they were in, they appeared resigned to it and felt unable to challenge health-care professionals. *"I felt that the decisions were made without us, and then we'd be invited into the ward round as a matter of courtesy to let us know their (professionals') plans. It's like when they said they were going to put him back on olanzapine. I knew it wouldn't work for him because it hasn't in the past, but I didn't say anything because the decision had been made and nothing I said would change that."* (study 5)

Acknowledgement of emotional needs
(n=4 study numbers: 1, 2, 5, 7)

Family caregivers expressed a need to be recognised and valued by health care professionals in order to feel involved throughout their relative's period

of hospitalisation. Admission of their family member to inpatient care was a time of distress and anguish for them, an emotionally difficult time that they felt deserved recognition and acknowledgement by health care professionals. A mother in study 5 whose son had paranoid schizophrenia stated: *"No one seemed to appreciate the impact his hospitalisation had on me. I just wanted someone to recognise the hell I'd gone through, to feel that someone cared about me."* (study 5)

Parents described the lack of advice and help to cope with the emotional aspects of the situation. "*Most parents are left in the dark and they don't have a clue, they have no idea what's going on. It's pretty devastating for parents, because you have lost your child, the one you used to know, and it's not that they are going to be worse, it's just that now they are a different person, and as a family member it's pretty hopeless and we feel very alone."* (study 1)

The carer as expert on the family member
(n=4 study numbers: 1, 2, 4, 5)

Family/parent caregivers talked about the unique and valuable role that carers could play in mental health services and care planning in particular. This related to the deep knowledge they had of the individual inpatient, which might otherwise be inaccessible to services. This knowledge, gained over the length of time they had been in relationship with the family member, enabled family/parent carers to develop a more detailed and holistic understanding, having known the person when they were well and unwell. Additionally, family/parent carers could contribute knowledge about

the interests and motivations of their family member, which the individual (inpatient) may feel unable to impart. One frequently mentioned aspect of a carer's knowledge was the ability to identify early warning signs of relapse which may become useful for crisis planning elements of the care plan. *"I can tell, I've got a little pointer thing, when [name] is starting to go off and… when his voice changes, that's the first sign."* (study 5)

In the included studies carers felt that their experience was devalued and that they were viewed as being less important and having less valuable knowledge about mental illness. A mother in study 1 observed that: *"There needs to be a realisation that we need one another and in fact, family members are the expert."* (study 1)

Study 2 reported that carers considered empathy and respect were essential attitudes for the creation of a collaborative relationship. *"If some of them [health professionals] were human instead of being officious we would get further. Some of them think they're up there [superior to carers] and what would you know."* (study 2)

Parent participants believed that they were viewed as threatening when they tried to be involved, and they were frequently met by a defensive attitude. A parent in study 5 stated: *"I'd like to be valued as someone who can contribute to my son's care. For that to happen, the attitude of the nurses and doctors has to change from 'they know best'. I have so much to contribute, but it's as though by asking me what I think it's challenging their knowledge and know-how and it's just silly. They're professionals in mental health. I am a professional about my son. It needs to be about working together. It shouldn't be about us and them."* (study 5)

Discussion

Summary

The aim of this systematic review was to synthesise qualitative literature exploring family caregivers' experiences of contact with mental health professionals. The review also considered family caregivers' preferences for and experiences of, participation in the care and treatment of a family member with mental health needs in inpatient care. The findings of the review show that family carers want information and advice about the mental illness and the well-being of the family member with mental health needs admitted to a psychiatric hospital. Furthermore, family caregivers need support in order to deal with difficult emotions related to being a carer of an adult child/relative with mental health needs in formal care, as well as inclusion and support for themselves, for their own sake.

In the present review, confidentiality is pointed to as one important obstacle to collaboration between family/parent caregivers and mental health professionals. Two specific difficulties or dilemmas concerning the confidentiality of information were reported. The first issue concerned the requested information being considered unnecessarily confidential. The second issue was the apparent conflict between keeping patient information confidential and at the same time allowing family/parent caregivers to confidentially provide information about the service user. Sometimes this had been respected, but a number of studies reported difficult situations had arisen when confidentiality was breached. From the parents' accounts it would appear mental health professionals found it difficult to keep patient confidentiality and at the same time be supportive to families, which confirms findings by Zipple et al. (1990) and Rapaport et al. (2006). This

dilemma was also described by Kaas et al. (2003) as a significant barrier to a well-functioning relationship between informal carers and mental health professionals. The potential for abuse and misuse of confidentiality was an emotive subject for some family caregivers who reported prior unhappy experiences regards application of this ethical principle. These findings are in agreement with an information governance review by the Department of Health (2013) which revealed professionals are not always clear about where the limits of confidentiality lie. According to Cree et al. (2015) these difficulties about confidentiality and information sharing identify a combined training need for the mental health patient, carers and professionals in order to improve relationships, ensure consistency and enhance stakeholder experiences of care planning processes.

The second overarching theme indicated carers need several things: support, by way of cooperation and dialogue; trust, and the ability to share their experiences and knowledge with mental health personnel. Advice, support groups and education were found to be important aspects of support as well. Carers in these included studies expressed their willingness to work in partnership with health care professionals, believing they are a valuable source of knowledge and have a significant amount to contribute. However, collaboration was often experienced as difficult, owing to the differing approaches of each party. Similar results have also been found in studies from past decades about relatives' need for support from professionals; such studies have shown that although relatives generally wish to cooperate with mental health personnel in connection with the treatment of their mentally ill family member, they find this difficult to achieve (Cleary, Freeman, Hunt, & Walker, 2005; Cleary, Freeman, &

Walter, 2006; Doornbos, 2002; Holden & Lewine, 1982; Jubb & Shanley, 2002; Winefield, 2000). In this review, carers found themselves alienated from professional care, an experience also reported in the study by Ewertzon, Lützen, Svennson and Andershed (2010) which described cooperation between staff and relatives to be a problem area in the sense that health care professionals do not value relatives or their opinions. The present review found relatives' resources mainly were unwanted by mental health staff. Their resources were in terms of an understanding of their mentally ill family member which was based on a wholeness of life-sharing experiences with the individual, and in terms of wanting to engage as a supportive part of his or her life. The family caregivers experienced that mental health workers lacked interest in their knowledge, which is in keeping with findings previously identified by Muhlbauer (2002). The results of the review are also in accordance with research by Pejlert (2001) and Rudge and Morse (2004), which demonstrated parents may experience arrogance on the part of the caregiving professional who claim to know the patient better.

Implications for practice

Whilst the review findings may prove uncomfortable reading for those associated with mental health service provision and hospitalisation per se, embedded within family carers' accounts are a number of opportunities and challenges to address.

The Government's mental health outcomes strategy: *No health without mental health* (2011), offers a relevant strategic framework for seeking to

address a number of challenges identified by the current review and the review findings would appear to evidence the strategy's statement:

"*Families and carers, young and old, often receive limited help and too often report that they are ignored by health professionals on grounds that they need to protect the confidentiality, and respect the wishes, of the service user. However, families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered*." [No health without mental health, 2011 p.33]

The professional guidance document, *The Triangle of Care- Carers included: A Guide to Best Practice in Mental Health Care in England* (2013), sets out six key elements of good practice for mental health professionals. Amongst these, the current review would indicate that the following key elements are particularly relevant: "*Staff are 'carer aware' and trained in carer engagement strategies*"; "*Policy and practice protocols re: confidentiality and sharing information, are in place*"; and "*A range of carer support services is available*".

The current review would specifically highlight the importance of training mental health staff in psychiatric hospitals in carer engagement, with a particular focus on the containing influence staff can have on carers during initial stages of the admission of their family member, and also with regard

to inclusion, communication and information sharing about the hospitalised individual.

Similarly, the findings of the review would highlight the importance of developing practice protocols on confidentiality and information sharing with patients' relatives and would advocate contracting with involved individuals regarding how and what will be disclosed. Developing individualised contracts would reduce carers' feelings of disregard and exclusion by services, and lay out clearly defined respectful boundaries, and increase flexibility in information sharing when dealing with parent/family carers of an adult relative.

The carer's need for information must be balanced with the service user's right to privacy (Szmukler & Bloch, 1997) and when consent is withheld professionals face an ethical dilemma between non-maleficence (i.e. not doing harm through failing to disclose) and beneficence (i.e. doing good by respecting the patient's wishes). Slade et al. (2007) propose a framework for best clinical practice, which makes an important distinction between "general information", which can always be shared without consent, and "personal information", which is new to the carer and where consent needs to be considered. In their framework, Slade et al. (2007) present a decisional-based model regarding what information to share, where the central mediating factor is clinical judgement. In addition, they suggest two levels of action, "organisational" (i.e. service level protocols) and "clinical" (i.e. professional responsibility of clinicians), which should both be considered in decision taking. The current review would advocate the need to introduce such frameworks as commonplace in inpatient psychiatric care.

Finally, the current review findings would support the need for identified staff members as a point of contact and source of information in order to reduce feelings and perceptions of impenetrable services, and encourage reciprocity and dialogue between mental health professionals working in inpatient services and family caregivers.

Strengths and limitations of the review

A strength of this systematic review is that it brings together isolated qualitative studies conducted in different parts of the world, and provides an accumulated understanding of families' experiences of caring for an adult relative in inpatient services, and family carers' experiences of collaboration with mental health professionals working in these settings.

Other strengths of this review are that the search terms covered a variety of terms, which the author believes adequately represented the area of enquiry. The search itself was conducted across a range of databases ensuring all types of disciplines (psychological, social science, medical) were included, increasing the variability of the studies.

Despite these strengths, it is important to acknowledge the limitations of this review. The review may be considered biased as it was conducted by one researcher. Although it is generally accepted that one person is able to conduct a systematic review, it is subject to the opinion of one individual and others may have placed different emphasis on different factors. It was due to time constraints and resources available, that the author was the only assessor in applying the study inclusion/exclusion criteria to retrieved studies, conducting both the data extraction and quality assessment processes, and deriving themes from the included studies. It is possible that

a second rater may have judged returned articles differently, which may or may not therefore have been included in the review. However, a limitation of this could have been the potential for a second assessor to exclude studies from the review, which would have limited even further what was already a small number of remaining articles, perhaps this was a consequence of the author's reasonably tight PICO structure. Upon application of the quality appraisal tool, all studies received an overall positive rating, suggesting that all employed appropriate design and methodology and demonstrated a rigorous and transparent approach to analysis and presentation of findings. Nonetheless, the addition of a second independent reviewer for this stage, and the ones preceding, could have potentially added weight to the reliability of decision making by the sole researcher, and would have enhanced the validity and reliability of the review findings, as well as credibility of review conclusions. If this review were to be repeated, it would take into account these limitations and be amended accordingly.

With the exception of a doctoral dissertation, this review contains only published research. Although the search strategy included unpublished theses and dissertations and no additional unpublished theses or dissertations were found that met the inclusion criteria, that does not mean more research on the review topic, does not exist. This may create further limitations in the conclusions of the review, as it may be a source of publication bias.

Finally, the inclusion of original research articles carried out with varying methodologies that draw upon differing epistemological stances, may be considered a potential limitation in this review. However, such concerns are

also queried for the value of being as inclusive as possible when selecting studies for review, as well as the potential to enhance the value of findings when studies of differing epistemological stances are reviewed alongside one another (Finfgeld, 2003; Sandelowski, Doherty & Emden, 1997).

Conclusion

By reviewing existing qualitative studies about the relationship between mental health workers and family caregivers of persons with mental illness in inpatient care, insight has been gained into how involved family members perceive they have been in the care and treatment of a relative experiencing mental health problems, and identified ways in which family members would like to be included in the care and treatment process.

The review findings resonate with some of the issues highlighted in the extant literature, in particular, carers' feelings of powerlessness and being isolated from the care planning process, and the mental health professionals failing to recognise and value informal carers as individuals in their own right. Ultimately the synthesis has revealed that in mental health care, family members are framed as outsiders and the general picture in terms of carer involvement is gloomy.

The recommendations arising from the review findings sit comfortably with the recommendations of current UK government mental health strategy and professional guidance documents, regarding how services may meet the challenges of including carers of an individual with a mental health issue in the care planning process, as well as inclusion and support for family carers themselves, for their own sake.

The findings of this review call for further research on the needs of specific carer groups, e.g. experienced carers, elderly carers, forensic carers and the development of interventions and resources that can meet the needs of these groups. Finally, in order to develop a collaborative orientated practice, it is important to document the view of staff too. One suggestion is to examine the relationship between family members and mental health professionals, and have the mental health professional perspective be the major focus of the review. An investigation into the perception of the relationship between health professionals and family members, from the viewpoint of nurses, doctors or other health professionals, would yield insights into how professionals in mental health services approach their work and how they attempt or do not attempt to accommodate family carers who seek to support family members with mental health needs.

Link between systematic review and primary research study

As outlined in the introduction of this thesis, much research has focused on the impact of having a family member with a diagnosis of mental illness, from the perspective of parents, and in the context of being the individual's primary caregiver. However, studies exploring family carers' experiences when their relative has been admitted to inpatient services and are formally being cared for by professionals, are more limited. Although there has been some research into family caregivers' interactions with the mental health system, and family caregivers' experiences of working with professionals providing support to a relative with mental health needs, it is important to expand our knowledge in this area, by considering the lived experiences of family caregivers who support individuals in forensic mental health services. What follows is an exploratory research study that has attempted to elicit and describe the meanings parents ascribed to the care they provide to their adult children in forensic mental health services and to assess how involved parents felt in the care and treatment of their relatives within a regional medium secure unit.

Chapter 2: PRIMARY RESEARCH STUDY

Parental perspectives: Being a parent of a son or daughter in adult medium secure forensic mental health care.

Abstract

Adult medium secure forensic mental health services provide care and treatment to individuals with complex offending and mental health histories. This research reports the findings of a study designed to explore the experiences of parents with an adult son or daughter with mental illness in a regional medium secure unit. This study is based on interviews with six parents using qualitative methods. Interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA). Four themes emerged: 'somethings not right'- onset of mental distress; 'going through hell'- experiences of violence and entering secure services'; 'it's a terrible battle'- relating with professionals; and 'a very sad fact of life'- caring with no end in sight. Parents' experiences were grounded in a changed temporal world. The onset of the mental distress was narrated as a fateful event that transformed the course of the family. Though they did not serve as primary caregivers, parental support emerged as a life-long effort to help the son or daughter affected by a mental health difficulty living in a forensic setting. Findings suggest that perseverance in the informal caregiving role is based on devotion to the adult son or daughter. The ways in which service delivery and research can be influenced by 'giving a voice' to parents is explored, and implications of the findings are discussed with reference to the current recognition of family and social inclusion.

Introduction

Background

Annually, mental health problems affect approximately 450 million people worldwide (World Health Organisation, 2001). In Britain, it is estimated that one in four adults experience at least one diagnosable mental health condition e.g. depression or anxiety, in any one year, and one in six experiences this at any given time (The Office for National Statistics Psychiatric Morbidity report, 2001). The risk of experiencing mental distress is significantly greater in prisoners than in the general population (Rutherford & Duggan, 2007). Studies have shown that the prevalence is so great, it affects as many as nine out of every ten prisoners, and about eight percent are considered to have psychosis (Singleton, Meltzer & Gatward, 1998).

Mental distress is characterized by experiences that may make individuals prone to behaviours which can lead to involvement in the criminal justice system (Forensic Psychiatric Services Commission, 2004). Although it is acknowledged in those cases where somebody with a history of mental distress is violent, the usual risk factors for violence (gender, alcohol or drug use, a past history of violent behaviour) are usually more important factors to consider (Understanding Psychosis and Schizophrenia, 2015).

Forensic mental health services exist to provide intervention and support for individuals who have been charged with an offence and are typically regarded as posing too high a risk to receive treatment within general psychiatry services, but for whom detention in prison would be detrimental to their mental health and access to regular mental health treatment

difficult (Walker, Craissati, Batson, Amos & Knowles, 2012). By the end of 2008, the number of mentally disordered offenders detained within a secure hospital setting in the United Kingdom was 3937 (3460 males, 477 females) the highest figure recorded in the previous ten years (Ministry of Justice, 2010). If people with mental distress who have never been involved in offending, cannot be safely managed elsewhere, then they might also be admitted to forensic psychiatric services (Copeland & Heilemann, 2011).

Informal carers including family members often play an essential role in the care of service users during periods of hospitalization. UK-wide developments such as the Triangle of Care, carer peer support, implementation of a recovery agenda for informal carers (Worthington et al., 2013; Machin & Repper, 2013), and the Royal College of Psychiatrists Partners in Care campaign, underline the importance of engaging family health carers across the UK. That said, it is recognised that research is urgently needed to provide a more secure evidence base for developing carer-centred services generally (Samele et al., 2007). Particularly lacking, is research that examines the perspectives and experiences of family carers, where the family member is in forensic (secure) mental health services, being looked after by professionals (Wood, Curtis, Gesler, Spencer, Close, Mason & Reilly, 2013).

A review of studies on family members' accounts of what it means to live with a relative with mental distress, showed they focused on three aspects of the parental experience: forms of parental caregiving, the impact of the diagnosis on the parental experience, and the changing nature of parental roles over the course of the child's complaints. They provide a useful

starting point to increase understanding of the meaning of being a family carer supporting a son or daughter in forensic (secure) mental health services.

Chesla (1991) provided an interpretive account of four forms of caregiving: engaged care, conflicted care, managed care and distanced care, which evolved in response to the demands of living with a family member who has severe mental distress. Parents who practiced engaged care were totally devoted to their child; providing unconditional, financial, social, and practical support. Engaged parents were more interested in fostering their child's self-esteem than improving his/her level of functioning and, thus, had difficulty setting limits or changing disruptive behaviour. Parents who used a conflicted care approach had difficulty balancing their child's needs against their own, becoming angry at the disruption in their lives and sometimes attributing their child's 'misbehaviour' to manipulation, rather than a problem of emotional distress. According to Chesla (1991) these parents tended to experience greater psychological distress than other parents. In the third form of caregiving, managed care, parents actively informed themselves about the mental distress through reading the available literature, and viewed their caring as intervention. However, managed care at times became overwhelming for some participants. Distanced care was exhibited mostly by fathers and characterised by a dependence on the child's mother to provide the direct care the child required.

Rose's (1998) findings indicated that "caregiving meant accepting a responsibility to influence the impact of the illness on the relatives' lives"

(Rose, 1998, p. 371). Furthermore, the meaning of caregiving revolved around three concerns. First, caregivers were concerned with finding the essence of the person obscured by the emotional distress and thus worked toward not losing sight of the person beneath the experiences or problems described. Second, the theme of finding a place for self in influencing the mental distress emerged, and was related to caregivers' attempts to develop routine responses to mental distress-related behaviours, which would make the condition better. A final theme, helping the relative to move forward, involved focusing on the future by setting goals, sustaining hope, and stepping back.

The work of Tuck, du Mont, Evans and Shupe (1997) drew attention to the impact of a diagnosis of schizophrenia, on parental caregivers of a son or daughter with mental distress. The study described two main stages, pre-diagnosis and post-diagnosis- outlining the parents' initial assumptions that the difficulties their child was experiencing reflected 'normal' adolescent development, until the behaviours became too bizarre and difficult to handle. The authors describe parents search for help as confusing, with different explanations from professionals, and a time lag between seeking help and an 'accurate' diagnosis. Whilst the diagnosis confirmed the presence of a 'problem' and offered some relief for families, the next stage was characterized by parents endless caregiving and learning to live with constantly changing levels of hope, and despair.

Milliken (2001) examined the parenting of 29 caregivers of adult children with a diagnosis of schizophrenia using grounded theory. The model of 'redefining parental identity' traces changes in their identity as parents, and the ways in which that identity impacts upon, and is impacted by, their

caregiving. Milliken (2001) argued as the child experiences less severe problems and then experiences more pronounced problems, his or her parents must redefine what it means for them to be parents of this person with severe mental distress. This role redefinition has consequences for their caregiving and vice versa. In the Milliken study, it was found that parents undergo this reformulation not just once but many times during the 'lengthy' and 'unpredictable course' of their adult child's severe mental distress. The stages in their process include: becoming marginalized, the disenfranchised parent, connecting with other parents in a support group, becoming actively involved in volunteer work, and latterly, refocusing on themselves and their own needs.

One challenge that disrupts the routine of caring for a family member with mental illness is when the person is hospitalised. Jankovic et al. (2011) explored how family caregivers of patients who were involuntarily admitted to a psychiatric hospital, experience the involuntary admission and subsequent treatment of their relative. Interviews with 31 family caregivers of patients who were admitted to 12 hospitals across England, revealed that family carers found it difficult to access support when their relative was becoming unwell and described these situations as very stressful. Furthermore, family caregivers disagreed with the clinicians' views regarding the level of professional support their family member required before, ultimately, being admitted to hospital. Family caregivers reported involuntarily admission of their family member triggered feelings of relief, as well as emotions of guilt and worry. Regards involvement of family caregivers during the period of hospitalization, family carers acknowledged problems relating to confidentiality and lack of information. Family

caregivers understood that confidentiality was a sensitive issue, but considered that if they were providing care for the patient they needed to know relevant information which would allow them to optimize their level of care.

Adding to the current understanding of being a family caregiver of a relative with a mental health condition receiving professional care, Ridley et al. (2013) conducted a study that aimed to provide evidence about existing support for family carers across forensic mental health services in Scotland; the extent to which carers accessed available support in forensic services; and what works well, in addition to what prevents carers from using support provided by forensic mental health services. Interview accounts from 19 forensic carers and questionnaire responses from 66 family carers or friends of individuals using forensic mental health services, resulted in key findings that both provision of carer support and the extent to which it may be accessed, are inconsistent within and between forensic mental health services in Scotland. Examples of good practice in the support of carers included: investment in information exchange, carer support groups and behavioural family therapy. However, confirming results of the study by Jankovic et al. (2011) who found that confidentiality is a delicate issue for mental health carers, forensic carers in the Ridley et al. (2013) study reported feeling barriers were erected, because of the right of the service user to confidentiality which limited dialogue between carers and professionals.

Mental illness is relevant to the risk of violence (Mulvey, 1994; Stuart, 2003; Walsh, Buchanan & Fahy, 2002). A number of studies have reported that persons with schizophrenia present a four to six times higher risk of

committing a violent crime compared to individuals in the general population who do not have a mental health condition (Angermeyer, 2000; Brennan, Mednick, & Hodgins, 2000; Eronen, Angermeyer, & Schulze, 1998; Hodgins, 1992; Hodgins, Mednick, Brennan, Schulsinger, & Engberg, 1996; Tiihonen, Isohanni, Räsänen, Koiranen, & Moring, 1997), although their contribution to the overall criminality in society is small (Swanson, 1994).

Research has shown that, when individuals who are mentally unwell become violent, family members or individuals who live in the same household as the individual with mental illness, are usually the victims (Estroff, Swanson, Lachicotte, Swartz, & Bolduc, 1998; Steadman et al., 1998; Nordström & Kullgren, 2003). It has been found that around half of the relatives of a sample of patients admitted to an acute psychiatric unit had experienced verbal abuse and/or threats, and about a quarter to a third had sustained physical injuries (Vaddadi, Gilleard & Fryer, 2002; Vaddadi, Soosai, Gilleard & Adlard, 1997). However, these reported figures could be biased by the fact that in this instance violent behaviour was one of the criteria for admission to the unit.

It has been suggested that accessibility of victims plays a significant role in violence perpetrated by individuals with mental health problems (Binder & McNiel, 1986; Nestor et al., 1995). Reid (2004) used the term "victims of convenience" to describe family members who often care for psychotic relatives and increase the risk of becoming a victim through simply being there.

Little is known about the experiences of parents who have been victims of this form of familial violence including, how parents understand violence adult children with mental distress direct towards them, and the attempts to get their child help and intervention when this occurs (Copeland & Heilemann 2008).

Of the studies outlined here, no research was found that examined the meaning of parental caregiving of adult children with a mental health condition who are in forensic mental health services, being cared for by professionals. Pejlert (2001) indicates the absence of studies might be the manifestation of an assumption that care in hospital settings for people with mental health difficulties leaves the family free from caring responsibilities. It can be argued however, that family relationships are life long and admission to a mental health unit simply signals the beginning of a different kind of involvement for parents (Ade-Ridder & Kaplan, 1993). Studies are therefore needed that will elicit families' experiences of caregiving when their relative enters forensic mental health services and are legally/ formally cared for by professionals.

Aims of the study

The aim of the study was to focus on parents, who care for adult children diagnosed with a mental illness receiving compulsory treatment and support in a medium secure forensic unit, with the following objectives;

(a) To explore the meanings parents ascribed to the care they provided to their adult children in a medium secure forensic mental health unit.

(b) To describe parents' experiences of engaging with mental health professionals as a carer to their child entering forensic mental health services.

(c) To elicit parents' views concerning the mental distress experienced by their child and what the person can expect in future.

Methodology

Design

In order to explore the lived experiences of being a parent of a son or daughter with mental distress in a forensic mental health setting, a qualitative design was considered most appropriate. Qualitative designs provide a flexible framework within which to explore how individuals make sense of certain events, the meaning these events have and how people have lived through or cope with these (Willig, 2009).

The present study employed Interpretative Phenomenological Analysis (IPA) (e.g. Smith, 1996; Smith & Osborn, 2003; 2008). IPA was chosen as the methodology for several reasons. Firstly, the utility of IPA has been demonstrated in psychological research. Initially gaining momentum in health psychology, there is now a growing body of IPA research in clinical psychology where there are unexplored areas of psychological interest and in answering questions about personal meanings (see Knudson & Coyle, 2002; Rhodes & Jakes, 2000). To date, there are no published studies exploring how parents make sense of – derive meaning from- their caregiving role, when this culminates in their mentally ill relative receiving compulsory treatment and care within a secure forensic setting. Secondly, IPA is consistent with the research aims; to explore in detail how participants make sense of their world to get an insider perspective (Smith & Osborn, 2003; 2008). The underlying philosophy being there is no objective reality, but rather people's experiences are influenced by their perceptions, which are constrained by social constructions. The researcher tries to make sense of the participant trying to make sense of their world, resulting in a double hermeneutic process (Smith & Osborn, 2003; 2008),

giving rise to both the phenomenological and interpretative aspects of the approach. The interpretive account produced is positioned in relation to the wider social, cultural and theoretical context, providing renewed insight into the phenomenon under study (Larkin, Watts & Clifton, 2006). Thirdly, IPA's idiographic nature matches the research objective; to report in detail about the participants rather than making premature general claims for the larger population (Smith & Osborn, 2003; 2008). Analysis aims to highlight generic themes, in addition to each participant's individual story, thus examining both divergence and convergence (Smith, 2004). It is suggested that delving deeper into the particular takes us closer to the universal and the 'essence' of experiences (Smith, 2004).

Other qualitative approaches that were considered included Discourse Analysis (Potter & Wetherell, 1987); Grounded Theory (Glaser & Strauss, 1967) and Narrative Analysis (Clandinnin & Connelly, 2000). Discourse analysis with its strong emphasis on language as social action and rejection of cognition's central role (Willig, 2008) seemed inappropriate for a study where beliefs and attitudes are explored. Grounded theory was judged unsuitable because of its positivist underpinnings and emphasis on theory construction (Charmaz, 2008). As one of the main limitations in family mental health research has been the tendency for a narrow approach at the expense of hearing alternative voices, IPA seemed more suited to explore the richness and complexity of individual experiences. Narrative analysis is often used when investigating experiences involving transitions and identity renegotiation. Concerned with the narratives people construct to bring order and meaning to the constantly changing flux (Murray, 2008), it gives voice to those absent from mainstream discourse (Collie, Bottorff & Long, 2006).

Although sharing similarities with IPA, the author felt narrative analysis's specific emphasis on temporal narratives might limit the research, whereas IPA's openness would allow for narratives to be heard if relevant. Accordingly, the author concluded IPA provided the best methodological fit with the research question.

IPA requires a data collection method which will invite participants to offer a rich, detailed, first person account of experiences. Semi-structured, one-to-one interviews have been used most often as they are particularly useful for in-depth idiographic studies exploring how participants make sense of experiences (Smith & Osborn, 2003). Employing semi-structured interviews as a data collection method maintains the aims of IPA as this method allows for the interviewees to be the 'primary experts' on the material in question (Alexander & Clare, 2004).

Other methods suitable for collecting rich verbal accounts that have been used include: diaries (Seibold, 2004; Sharp et al., 2004) and focus groups (Dunne & Quayle, 2001). Focus groups can be useful when people have a common experience and, despite the absence of availability of a carer support group at the regional medium secure unit which hosted the research, through which potential participants could be identified and contacted, it may have been possible to use this form of data collection in the current study. However, a criticism of focus group discussions is that they may not be sufficiently in-depth to gain a good understanding of individual participants' experiences (Liamputtong, 2009). Parent participants may also have felt unable to talk freely in front of other parents, thereby increasing the potential of missing important issues (Michell, 1999).

Flowers, Duncan and Frankis (2000) reported finding differences in data from interviews and focus groups, with interview data being more detailed. Diaries were not selected for use in the current study because this method of data collection requires respondents to make regular records of their daily activities and experiences (Mariño et al., 1999; Bowling, 2002). The researcher considered the possibility that parents may have viewed this as involving too much effort and be less inclined to want to take part in the study. Verbrugge (1980) and Wheeler and Reis (1991) acknowledged that as the diary period lengthens, participants become tired of keeping records and may become less thorough in their reporting.

Taking the above points into account, the data collection method of semi-structured interviews was chosen over focus groups and diaries. Semi-structured interviews grant participants the opportunity to tell their stories, to speak freely and reflectively and to develop their ideas at some length (Smith, 1995). The semi-structured interview provides the researcher with much greater flexibility than a questionnaire or a structured interview as it allows the researcher and participant to engage in a dialogue whereby initial questions are modified in light of the participant's responses, and the interviewer is able to enquire after other interesting areas which arise (Smith & Osborn, 2008). As the topic of study concerns discussing personal and sensitive material, the semi-structured interview is particularly suited to the collection of such information and it is an approach which will allow participants to discuss their personal experiences in a way they are comfortable with (Mack, Woodsong, MacQueen, Guest & Namey, 2005).

Setting

The study took place at a regional medium secure unit within an area of the UK, which provides in-patient treatment and care to male and female patients over the age of 18 years with forensic mental health problems, in a secure therapeutic environment.

The clinic has three wards. Ward 1 is an admission and assessment unit, with twelve beds for male patients only. Ward 2 is a twelve bedded mixed gender ward. Ward 2 has five beds that can be made available for female patients, although this is not a dedicated provision. Ward 3 is a rehabilitation ward for male patients and has ten beds.

All patients admitted to Wards 1 and 2 are detained in accordance with the Mental Health (Northern Ireland) Order 1986. Patients may be detained in accordance with Part Two of the Mental Health (Northern Ireland) Order 1986, which relates to civil detention. Patients may be detained in accordance with Part Three of the Mental Health (Northern Ireland) Order 1986, which is also known as a Hospital Order. Patients may be detained under Part Two and Part Three of the Mental Health (Northern Ireland) Order 1986. Ward 3 patients are detained in accordance with the Mental Health (Northern Ireland) Order 1986, although patients in Ward 3 may be re-graded as voluntary status and remain at the unit until accommodation in the community becomes available.

Patients are referred to Ward 1 from various sources including the courts, prison, other inpatient facilities and the community. Male patients are transferred to Ward 2 from Ward 1 following a period of assessment. Female

patients are admittedly directly to Ward 2 from various sources including the courts, prison, other inpatient facilities and the community, and remain there until discharge. Male patients transfer from Ward 2 to Ward 3 for a period of rehabilitation.

Referrals to the clinic are assessed by the multi-disciplinary team to establish if the referral meets the criteria of a medium secure unit and the needs of the patient can be met appropriately.

Participants

A purposive sampling strategy was used to identify individuals meeting a number of specific inclusion criteria.

In step one, service users were approached to invite their parents to take part in an interview if they had (a) a functional psychiatric diagnosis of psychosis – schizophrenia, schizoaffective or other psychotic disorder for a minimum of six months established by a Consultant Psychiatrist; (b) were 18 years or older; (c) stable with regard to their mental state as determined by a Consultant Psychiatrist; (d) resided in the medium secure unit for at least six months ; (e) had capacity to provide informed consent and (f) were in regular contact with a parent or guardian.

Patients with these diagnoses were chosen because many research studies that have explored the lived experiences of parents with an adult child with mental illness, have focused on these mental health conditions in particular (see thesis introduction and the introductory section of the current chapter for examples). The researcher wanted to add to the existing knowledge base in this area. Furthermore, research shows an association between

these mental illnesses and violence and the aim of the current study was to understand the meaning of parental caregiving with reference to having an adult child with mental illness detained in a forensic setting. It seemed reasonable to expect that mental illness in combination with previous episodes of violent and aggressive behaviour may have led to these sons or daughters being admitted to forensic mental health care services. Patients needed to have a settled mental state to understand and consent to the study that was being undertaken and give permission for their parents to be contacted about the research.

In step two, parents contacted through their adult children being treated at the secure unit had to be: (a) willing to communicate their experiences to the researcher and (b) able to speak and read English.

The lead researcher had completed a 12-month placement in the medium secure unit, but was not a trainee there when the research took place. Recruitment of patients and parents was possible with the aid of a local collaborator approved to work on the study and other staff at the medium secure unit (Consultants and clinical teams).

At the time of data collection, the 34 bedded unit was at full capacity, comprising 32 male patients and two female patients. Ward 1 patients (n=12) were excluded from the prospective patient sample because, typically the individuals being admitted to this ward have an unstable mental state and at the Research Ethics Committee hearing (April 2012), the researcher was advised individuals in Ward 1 should not be contacted. Therefore, the number of potentially suitable patients that could be approached was 22. Of the 22 remaining patients that were possibly

eligible, it is not known how many patients fulfilled all of the patient inclusion criteria and were provided with study information, nor is it known the number of patients who were not informed of the research project, as well as the reasons why. The researcher was at the mercy of the recruitment process approved by the Research Ethics Committee, and the above unknowns point to the many levels of gatekeeping in place from beginning to end of the exploratory research project.

Seven signed patient consent forms (five from males and two from females) were collected by the local collaborator, and forwarded to the lead researcher. All seven patients gave permission for their parents to receive study information. Two patients (one male and one female) consented for their mother only (n=2) to be contacted about the study. Five patients (four males and one female) consented for both parents (n=10) to be sent study information. One male patient, who had initially given permission for both parents to be contacted about the study later withdrew his consent, and that meant his parents could no longer be included in the prospective parent sample. Therefore, ten parents were approached (in writing) to take part in the research.

Seven parents made contact with the lead researcher advising they would like to be considered for participation in the study, and three parents did not respond to written invitation to take part in the research.

Seven parents met the inclusion criteria and agreed to take part in an interview. Heavy snowfall prevented one interview from taking place, and after another meeting date had been arranged, the individual then changed their mind and withdrew from the study.

Interviews took place over a two-week period in January 2013. Three mothers and three fathers participated in the study. Four of the six parents were married (both couples consented to be interviewed). The other two parents (one male, one female) were divorced from their spouses. All interviewees were over 50 years of age, and more than half of these were aged between 55-65 years. Of those interviewed all except one parent identified their ethnicity as White British, the other study participant identified themselves as White Irish. All six parents had other children in addition to the son or daughter diagnosed with a mental illness. Two participants (mother and father of the same patient) had been living with their son at time of admission to the forensic secure unit. All six of the participants had experienced verbal aggression and/or physical violence from their adult child, although never reported the violence formally. Three of the parents had witnessed their son or daughter direct violence towards themselves (self-mutilation). All six parents were aware of their son or daughter's aggressive and violent behaviour outside of the family. In some cases, this related to the index offence, although with regard to anything criminal, parents provided the least information in interview with the researcher.

In order to ensure anonymity, pseudonyms have been used throughout and identifying information has been removed. Table 6 displays basic information for each parent participant.

Table 6. Characteristics of family caregivers

Pseudonym	Marital Status of participant	Relationship to patient in medium secure unit	Caregiver living with patient at time of admission	Length of time caring
Tessa	Married	Mother	No	>15 years
Chris	Married	Father	No	>15 years
Kate	Married	Mother	Yes	>5 years
Adrian	Married	Father	Yes	>5 years
Alice	Divorced	Mother	No	>10 years
Thomas	Divorced	Father	No	>5 years

Data collection

The clinical team at the medium secure unit identified patients who met study inclusion criteria. Cases were discussed with the patient's Consultant who approved which patients from this group could receive information about the study.

Eligible patients were given a cover letter and information sheet by the clinical team at ward round. The patient was asked if they would be willing for a member of their care team (the unit's Clinical Psychologist who acted as local collaborator for the study), to go through this information with them at a suitable time and answer any questions.

After a 'cooling off' period of at least 24 hours following discussion between the patient and the Clinical Psychologist (local collaborator), the patient's decision about permission to contact their parents in writing about the study was followed up by this staff member.

Since family members were being identified and recruited by the patient at the medium secure unit, it was ethically necessary to obtain consent from this individual prior to approaching their parents.

The researcher made weekly contact with Consultant Psychiatrists for each of the clinical teams at the unit to check on progress of recruitment. Signed patient consent forms were handed over to the lead researcher, by the local collaborator.

The Consultant Psychiatrist for the patient signed a cover letter to the parent introducing the researcher and this, along with a participant information sheet (parent version), which explained the purpose of the study and what would be required of their involvement, was sent to parents of patients who approved contact. These forms were posted by the lead researcher after a period of seven days. The Research Ethics Committee stipulated that the Consultant Psychiatrist should sign the parent cover letter introducing the lead researcher. Having the Consultant's signature on the cover letter notified parents that the clinical team were aware the study was taking place and staff had agreed to help the researcher make contact with parents in an ethical way. This was the last step that involved reliance on the staff at the medium secure unit. It was after this point had been reached that the Research Ethics Committee permitted the researcher to be more connected to the recruitment process.

Parents who were considering taking part in the study contacted the lead researcher where they were given the opportunity to discuss the research further. The direction of contact, parents calling the researcher and not the other way round, where the researcher telephones the parent after they

have received study information, was another requirement specified by the Research Ethics Committee. When a parent called the researcher, checks were made to ensure that they met the study inclusion criteria. It was the researcher's judgement as to whether the parent had capacity to give valid consent. This decision was arrived at after taking into account a parent's spoken understanding of the research project information that they had received, the parent's spoken ability to weigh up options regards participation and the parent's ability to assert themselves/express a real choice in this particular situation. During this phone call verbal consent to participate in the study was sought, participant's rights were discussed and interview arrangements were made. When parents met the researcher in person, written consent was obtained and recorded on the consent form.

Although the clinic was hosting the research, the input of the patient's care team, including the Consultant Psychiatrist to the recruitment process, had finished at this point. The Consultant Psychiatrists did not know which individuals, from the group of parents whom had been sent study information, chose to contact the researcher because they wanted to take part in the study.

Participants were offered a choice of interview location; at the forensic mental health unit in a location away from the ward areas, or at a location of their choice. This was in order to enhance participant choice and control within the research process with the aim of minimising any power differential inherent in the researcher-participant relationship. If the participant chose to be interviewed at their home, lone working procedures were followed to ensure safety. Two of the five interviews were carried out in Health and Social Care premises and the remaining three took place in

the parent's home. One joint interview was undertaken at home, that involved a mother and father relating to the same family member. The length of the interviews varied from 50 minutes to 90 minutes. At the start of the interview, the information sheet for parents was reviewed, participants were briefed about the interview process and consent forms were signed. The semi- structured interview schedule (appendix 16) was used in a flexible manner in accordance with IPA guidance Smith et.al, (1999). As the author had no previous contact with participants, the interview process was guided by the information they chose to share.

Ethical considerations

This study was reviewed and given favourable opinion by the Research Ethics Committee for Northern Ireland. Research Governance approval was granted from the Belfast Health and Social Care Trust (see appendix 7).

Clinical staff, service users and parents were informed verbally and in writing about the study (see appendices 8-10). The information contained the rationale and study aims, as well as the design procedures and duration of the research.

Participants were also informed about the voluntary nature of their taking part and that anonymised interview excerpts may appear in published material.

Written informed consent was obtained prior to the start of the interviews and all participants were informed of their right to withdraw at any time without any consequences for them, or for the continued care and treatment of their family member with mental health problems (see appendices 14 & 15).

The limits of confidentiality were discussed before each interview and participant's names and their families were changed to pseudonyms.

The researcher was aware that the interview may evoke painful memories for participants and that parents may become emotional when talking about their mentally ill son or daughter. The researcher was a forensic psychologist in training who had undertaken specific training to carry out these interviews and would have been able to support interviewees and handle sensitively, difficult situations that arose.

As the interviews focused on situations which may be related to strong emotions, time was permitted at the end for reflection on anything that may have arisen during the interview.

Whilst it was hoped that the interview would not expose relatives to any additional distress, information about available support and guidance was prepared and given to interviewees in order to signpost parents to appropriate agencies.

Data analysis

General guidance recommends using IPA if the researcher has a smaller sample and wants to know, in detail, what the experience for this person is like, what sense this particular person is making of what is happening to them (The University of Auckland, n.d). Guidance recommends using thematic analysis to address research questions that are not about people's experiences or perspectives, when the data do not capture first-person accounts of personal experiences, and when working with larger samples (The University of Auckland, n.d).

The researcher concluded the analytic method of IPA was better suited to gain an understanding of what it means to be a parent with a son or daughter in adult medium secure care and therefore the interview transcripts were analysed using IPA, as detailed by Smith (Smith, 1996; Smith & Osborn, 2003; 2008).

Additionally, the researcher had received university based teaching on IPA during her master's degree, and was taught as part of the qualification in Forensic Psychology being undertaken. Subsequently, the researcher attended a two-day training course (10- 11th November 2011) provided by the Centre of Qualitative Research, Bournemouth University, which provided further opportunity to develop skills and confidence in using this qualitative analytic method.

In analysing the data, transcripts were read and re-read a number of times as a way of becoming familiar with the personal meaning and key points of each account. This was also done whilst listening to the original recording. Initial thoughts and comments relating to aspects of the transcript were noted in the left-hand margin. The next stage of the analysis involved noting emerging themes, that capture the essence of what was said, in the right-hand margin. These themes were written onto separate pieces of flip-chart paper (one sheet per participant interview), in the order they had arisen within the data set. Commonality and difference were noted and connections between themes were made to produce larger, superordinate categories. This procedure was carried out for each interview. When themes had been produced for each individual set of data, patterns were then established across cases to form a master set of themes for the group.

Theme names were developed through using interview extracts which appeared to most closely capture the essence of the theme.

Validation methods

The influence of the researcher is recognized to be important in IPA and relies on the researcher adopting a reflective stance towards the research. In order to ensure that the research process was transparent, a reflective journal was kept throughout the research which documented the lead researcher's pre-conceptions, thoughts, feelings and impressions generated by the research and acknowledged the potential impact of these on engagement with the data.

Regular supervision (skype meetings) took place between the lead researcher and a member of the research team who has many publications using the IPA approach. During development of the interview schedule, this individual ensured that the questions were appropriate for the participants and did not include leading questions.

As a means of quality and credibility checking, the same individual audited two of the transcripts to check that initial themes and ideas were grounded in the data and to ensure that the process of deriving the themes was evidenced. The IPA supervisor also checked that each of the final themes could be directly linked to individual participant data.

Characteristics of the lead researcher

IPA assumes that interpretations arise from an interactional process between interviewer and interviewee (Smith, 1996), therefore it is good

practice to reveal contextual factors that may have influenced the study (Stiles, 1993).

The lead researcher was a 30 year old female undertaking the research as part of her training in Forensic Psychology. She had little experience of working with family members of individuals diagnosed with mental illness, but had five years of experience working with people with complex offending and mental health histories, including conducting sensitive interviews. She also had an interest in parents' experiences of seeking help for children with severe mental distress and the meaning of parental caregiving of a hospitalised son or daughter.

Results

The aim of the interviews was to explore the experiences of forensic carers with a son or daughter diagnosed with a mental health condition living in a forensic medium secure setting. Each parent carer provided rich and detailed descriptions of their experiences of caring for their son or daughter with mental health difficulties. For all, this was a journey that was unanticipated and unplanned. In effect, the caring role had taken over their normal life and resulted in parents embarking on a new and challenging journey during which they had little knowledge or advice. The participants' accounts, while being unique to them, nevertheless revealed a number of common themes that were a feature of the complex and challenging experience of caring for a son or daughter receiving treatment in forensic mental health services (see Table 7). These themes, which were derived from participants' reports of their experiences, were consistent across parent carers' accounts and have been termed "something's not right"- onset of mental distress; "going through hell"- experiences of violence and entering secure services; "it's a terrible battle"- relating with professionals, and "a very sad fact of life"- caring with no end in sight. Each theme will be discussed in turn, illustrated by quotes from the parents who took part in the study. The quotes offer examples of how the themes are grounded in the data.

Table 7. Summary of themes

Super-ordinate and Sub- Themes	**Illustrative Extract**
"something's not right"- onset of mental distress realising trying to make sense in uncertainty	*"She lived with a boyfriend that [ ] she attacked [ ] a couple of times, wreckedhis house and cut his face [ ] and that's when I started, here's me something's not right here."*
"going through hell"- experiences of violence and entering secure services	*"She did make a go [ ] before she was hospitalized [ ] she was going to hit me [ ] we used to hide knives [ ] in the house [ ] we got rid of them in case things happened."*
"it's a terrible battle"- relating with professionals ignoring the parents lack of information	*"It took me two years to fight with the hospital [before I] finally won through that they accepted that she did have a mental problem. Well, it was a terrible battle and I know an awful lot of people who still sort of have that battle."*
"a very sad fact of life"- caring with no end in sight getting a diagnosis facing change and loss staying connected bearing the burden hoping for a better life	*"anybody else [ ] going down this road are going to start off the same as us with the belief that this is all going to come to an end [ ] then one day you realise that it's not going to get better [ ] don't build you're hopes too high with this illness, in some cases this illness will go on for a life time."*

Theme 1

"Something's not right"- onset of mental distress

Parents had a strong sense that something was wrong with their child before help was sought and/or a diagnosis was made. Their words point to the often-overwhelming feeling of 'knowing-but-not-knowing': The super-ordinate theme "something's not right" contains two sub-ordinate themes 'realising' and 'trying to make sense in uncertainty'.

1.1 realising

This sub-theme characterises the early experiences of parents in their beginning to notice changes during the onset of their adult child's mental distress. Some participants recalled when they first noticed their adult child's mental health difficulties with vivid memories of their son or daughter showing distress. However, without prior knowledge and understanding of mental ill health, many parents described the difficulty in interpreting what they now perceive as early warning signs.

Kate recounted first becoming aware of her son Patrick's difficulties with a description of his psychosis.

'....in our bed, you pull the drawer out to get to your bed linen and you pull it, he's [son] in under it. Well, he didn't say at the time he heard voices. I didn't know, and he kept saying "There is somebody in here". He was in the built-in wardrobe…He was up in the loft. He had broke all his walls, broke everything (tearful). "They're in there. They're in there, between the walls…" He's right up into me like, going "You're going to tell me they're not ..." "There is nobody in this house [son]". And he was thinking we were lying [to him], and I was thinking "What's he thinking?"... I didn't realise as much'. (Kate)

A strong parental intuition that something was wrong was evident within the interviews. This seemed to reflect parents having an intimate relationship with their son or daughter. The observed changes could

manifest in rapid mood fluctuations that could take the form of physically aggressive behaviour, and alerted parents to the fact that something was amiss. Tessa asserted:

'She lived with a boyfriend that was a sergeant in the Police and aye, she attacked the sergeant a couple of times, wrecked his house and cut his face and all with a glass and that's when I started, here's me something's not right here and I brought her home here, 'coz I was afraid of her getting the hold of his gun and either shooting herself or shooting him. Here's me we'll bring her home and, you know, we'll sort of try to cure her, we thought, and what a time that was … just all at the start'. (Tessa)

Mothers and fathers became concerned primarily about how the child's behaviours were interfering with his or her ability to engage with or be successful in family, work and recreational activities.

Thomas, an outgoing father with a close circle of friends acknowledged his son John's difficulties because his behaviour differed significantly from siblings and peers.

'I was saying 'til him "You are young. Go out and have the craic, mix" ... I met up with my friends. He was made more than welcome. But my friends would say like, he's sitting on the fringe …He [son] can't walk the walk. See he's brother that hung himself, streetwise. He could have pulled women. He could have hustled. John was complete opposite'. (Thomas)

1.2 trying to make sense in uncertainty

A striking element in the parent's experiences was the uncertainty that seemed to envelop their child's mental health condition. Many accounts were littered with '*You're not sure*', '*I don't really know*' and '*I can't figure it out'*.

The parents started to question themselves though this logical reasoning was not enough to arrive at an acceptable explanation of their child's

condition. The following extract from the interview with Alice illustrates this kind of rational questioning and may represent one component of an awareness process in which parents try to reorient themselves to their situations.

'I sometimes wonder, you know, these voices… Are they voices or are they thoughts? You know, are they just angry thoughts? You know, the way you'd see a kid and they'd go slam a cup down or something like that or something you know. I mean that's an angry thought … but, I mean, maybe an angry thought for her is thinking about, I want to do this to that, maybe do this to that person, or that. Is it just sheer? Is it just sheer anger or frustration, or you know, I don't really know'. (Alice)

In trying to understand the changes during the onset of their son or daughter's problems, caregivers appeared to build a psychological model. The specific content of these frameworks differed, but common to all was drug use. Others incorporated vulnerability factors and psychosocial triggers to explain how the observed mood and behaviour disturbances came about.

'I didn't know whether it was something she was born with, something that would have happened anyway whether she had ever seen a drug, none of us know. I dunno whether …she had been in an accident em, when she was fifteen, quite a bad accident aye, and whether that had anything on her, 'cos she started sort of hyperventilating and stuff like that, ever from that, or whether it was just too many drugs that had actually damaged her brain or whatever, no idea'. (Tessa)

Thomas appeared to be in a greater struggle to make sense of how the difficulties came about. Perhaps because he described himself as a friendly, outgoing person and his other son who committed suicide reportedly had good social skills too, there was more difference to explain.

'There is nights I lie awake thinking about it, you know what I mean. But I can come to no conclusion. There's times I tried to stop myself thinking about it because it would put me loopy'. (Thomas)

Tessa's remarks below illustrate the extraordinary jumble of emotions that parents can feel when the causes of their son or daughter's unusual and challenging behaviours are opaque. This mother's comments also indicate that parents sought expert knowledge from any source thought to be reputable.

'At the start, ye didn't know what end of ye was up, ye didn't understand much, we done a lot of reading up and you know, trying to educate ourselves about the thing'. (Tessa)

Parents often described feelings of responsibility toward their child's condition- that the condition had arisen due to their failures as parents. In this way their skills as parents came under self-scrutiny. The account from Thomas below acknowledges a degree of self-accusation, as he started to question himself and how he had acted towards his son.

'I'm not saying I parented the best way ye can. I should have been there more often than I was, but then that was their choice too, the door was always open to him. But the thing is …I should have pushed it more... if you push it too much they don't come near you at all … it's like a tight rope walker'. (Thomas)

Theme 2

"Going through hell"- experiences of violence and entering secure services

Enduring abuse, aggression and violence permeated the day-to-day lived-world of all mothers and fathers interviewed in this study. The forensic carers made reference to the belief that mental illness is associated with risk to the individual as well as risk to others. Consequently, the parents acknowledged feelings of anxiety, being powerless, and vulnerable. Despite the abuse and assaults, the interviewees determined that they would persist in their role as a family caregiver and try as best they could to manage increasing difficulties. The extract from Tessa below illustrates how parents attempted to cope amidst the building sense of impending danger.

'She did make a go, and one time, in the house before she was hospitalized, well the dad thought that she was going to hit me, sort of thing. Right fair enough. Have to say, we used to hide knives and stuff in the house, just in case, any big knives or anything…. we had, we got rid of them in case things happened'. (Tessa)

Participants described repeated times of crisis which were terrifying and meant they had to call the police to assist them in managing their mentally ill family member. Kate said as follows:

'I usually would have phoned them [Police] if he got out of hand …Patrick could get aggressive… he knew rightly I would phone the police, [son] 'Oh you go on ahead to your wee button'. 'coz I have a security thing … and he would've bounced into the kitchen or run upstairs, like, 'Let them come on!' I just went 'Well that's okay Patrick. But, you do know you're not staying here' … I was stressed out' (Kate)

For more than half of the parents in this study getting assistance and accessing mental health treatment was a multistep process, as once the Police came to the family home, parents needed to persuade the authorities

to take their family member to the hospital, and then convince the health care providers to keep the ill person in the hospital.

The following account from Adrian outlines the sequence of alarming and difficult events leading up to his son's admission to mental health services.

'He went for an awful, awful long while that we couldn't get help from anybody or anyone. I don't care what anybody says, we could not. We tried everywhere… Now the day that he [son] came in here, and he was actually trying to cut the wire out of the back of his head. He said "Look feel it, feel it" … There's nothing there son…he was actually trying to cut that out with a Stanley knife, and he had also tried to put something up his nose so that we would always know where he is and then we'd have got the Police. Now we coaxed him to go down to the Doctors and … I'm not even going to go on too much about him [Doctor] …he seen the marks of him trying to cut things out of the back of his head and all, do you know what he give my Patrick? Antibiotics! … That's what he give him, and it was inside a week that my Patrick come in here and he says "I need help" and we rung the Police and this and that and the Police came out. To cut a long story short, he [son] said to the Police "Now don't be bringing me to hospital or anything, to be sitting there for ten or eleven hours, because I'll do a runner" … so we got on the phone and they [Police] got on the phone, and on the radio they [Police] says bring him up to [secure unit] right away, so we brought him up to [secure unit] right away, and then the girl that we were talking to told him that he was being detained under the Mental Health Act'. (Adrian)

Parents described the immense impact of caring for their child before a diagnosis was made. They often used striking images to convey the significance and emotional impact of the mental distress.

For the parents in this study, the process of getting assistance initially involved a period of hypervigilance in which they felt as if they were living on high alert. This was an intense period of watching what was happening and coping with the problems their children were creating. One mother discussed her situation as follows:

'We went for years not sleeping me and him [husband] because when she lived in (place) we used to drive over three and four in the morning because she would have kept sunbeds and all lit in the house, and you know she was fantasising, and doors would have been left open and all you know, so we couldn't sleep with the thought of it … and you never knew if the house was going to go on fire … so for a long time we never really got sleeping 'coz you were watching and a heart afraid of something going on'. (Tessa)

Adrian described a similar period of growing fear and escalating uncertainty about the risky behaviours his son engaged in, believing that he might meet an untimely death.

'He just run the streets. Sometimes on his own, sometimes with people yeah … I was out there four and five o'clock in the morning going up and down entry's looking for him, and he was living rough off the streets. See when the phone rung or the door wrapped or anything? He's dead! That's what in my head, and in my gut, and that's what I have been living through for years and years and years. Not only me, the wife is the same. We have been going through this absolute fucking hell, for years. And I meant that' (Adrian)

Admission to the medium secure forensic unit became a way of acknowledging that parents could no longer cope, at least not with the crisis that developed prior to entering forensic services. All parents were easily able to state this. They admitted that they could not cope, and were relieved that someone else was taking over. As well as the sense of immediate relief experienced by most families at the time of admission, recuperation of physical and emotional strength was also described. For example, sleeping patterns returned to normal.

Thomas stated: *'He's safe. To me, the thing is he is safe … I have already lost one son; I don't want to lose another one … I know I can go to bed at night, I don't have to wait on a phone call coming saying, you know, he's lying somewhere, I feel content that he's in the unit. A lot of pressure [is] off'.* (Thomas)

Without exception all forensic carers interviewed reported an absence of stigma related to their child's admission to forensic mental health services.

'I have no shame or nothing, you know. At the moment that's the best place for him, there's nowhere else for him, unless … If he was let out, God knows what he'd do … Like he's there, it's for his benefit, that's the way I look at it. I am not ashamed of it. Anybody that knows me knows where my son is at, like I wouldn't be one to get embarrassed about telling anybody about it'. (Thomas)

'I don't feel that I have anything to be ashamed of, I would never deny where Claire is except … and there are exceptions … except there are certain people that I know who would ask about Claire purely in a nosey manner, they don't give a rat's arse what happens to Claire, but they are nosey enough to ask …. Outside of those, any genuine people I have nothing to hide. My daughter is ill, if she broke her leg you would be saying to everybody aye, she has got a plaster on, she broke her leg …. Her mind is broken, simple as that'. (Chris)

Theme 3

"It's a terrible battle"- relating with professionals

This theme describes the relationships between parent caregivers and mental health professionals at two different time periods: pre- and post-admission of the family member to forensic mental health services. It outlines the challenges of parents in accessing and receiving help from mental health services. Participants felt strongly that helping professionals initially negated their concerns and did not take their reports of mental distress in their children seriously. The majority of parents stated that professionals did not provide them with adequate information about the child's mental health condition and care plan. The super-ordinate theme "It's a terrible battle" contains two sub-ordinate themes 'ignoring the parents' and 'lack of information'.

3.1 Ignoring the parents

The process of searching for professional support was often characterised as a new source of stress, which increased the level of burden parents experienced. Participants talked about how much onus was on themselves as parents to find out what was available.

Several parents described struggling to know what services were available to adults with mental health issues and when and how to access these services. An extract from Kate signifies a mother's fiercely committed efforts to identify appropriate treatment facilities and enlist help for her son.

'It was probably … 2010 – 2011 it would have been, 'coz we didn't even know that unit existed. 'Coz I sat one day and I went through the whole phone book … right down. You name it … I phoned everywhere'. [tearful] (Kate)

All participants reported an initial tendency among helping professionals to negate their concerns about their children. Consequently, participants sense of helplessness and hopelessness escalated, together with feelings of anger and disempowerment. An extract from Tessa below, highlights the difficulty she had convincing experts that her daughter Claire required formal admission to the mental health system.

'He [Doctor] says I'll make an appointment for you for Sunday morning to go down to the (hospital) and then gradually, but even then they still wouldn't say it … until many, many years down … and then I think they realised there was more till it than that, you know …. It took me two years to fight with the hospital [before I] finally won through that they accepted that she did have a mental problem. Well, it was a terrible battle and I know an awful lot of people who still sort of have that battle' (Tessa)

Parents' caregiving knowledge was indirectly being challenged by Doctors as most were told at some stage that they were overreacting. What came across strongly in these accounts was a sense of outrage. For example, the narrative from Chris conveyed feelings of being furious with the professional he sought help from for his daughter, and the willingness to call health professionals to account.

'We had been fighting for ages for somebody to tell us, but they wouldn't tell us, and even on one occasion I took her, she came into the house crying, crying sore … and I took her down to the hospital and sat with he,r and eventually they seen her and the Doctor says 'til her "Ach you'll be alright, I'll give you a couple of pain killers, go away on home there, you'll be okay". I says, "I want you to repeat what you just said in front of a witness, because when she goes outa here and harms herself or somebody else, I'm taking you to court'. (Chris)

Parents' lived experience was not being validated and this becomes especially problematic if the adult child presents 'well' on the day. Tessa's comments indicate the professional she sought help from for her daughter

felt that she was the person with a problem, and elucidates the difficulties parent caregivers have had in the past trying to get professionals to listen to and believe the family's side of the story.

'Nobody was willing, aye, even to diagnose her as being schizophrenic at the start. For they were trying to tell me it was me that was mental, aye, rather than her. Because they couldn't see….Because they could ask her, her name, aye. Where she lived… and she could answer them … It was as much as "There's nothing wrong with her". They don't see her when I seen her…where she was really in a bad way, maybe going to kill somebody or kill herself.' (Tessa)

Parents described a general sense of responsibility towards their son or daughter who was seen as vulnerable because of their mental health condition and the longer concerning behaviours went on, the more desperate parents' plea.

'Jen's self-harming was just, just awful … It was just constant and erm… He (Doctor) sat there and he said to me "Your daughter doesn't have a mental illness" and I said erm.. "Okay, that's your opinion". I says, "Who in their right mind would do what she has done to her arms and legs?" I says "She is … her arms are cut from top to bottom", … I mean it was just horrific, you know … Now over the years a lot of it has faded, but at the beginning when it was just like cut, cut, cut and it was just really …. the injuries were just really terrible, and had to be stitched and all this sort of thing'. (Alice)

Chris voiced his frustration that assessment did not happen earlier, suggesting that entering forensic mental health services much sooner would have prevented further deterioration of his daughter's mental health.

'I believe she would never have got as ill as she did had they [Doctors] took the whole thing in hand earlier when they were told. We run after Doctors. We had situations where Claire was jumping out of the car when we were driving and we have been to hospitals, we have been to all sorts and nobody would actually say what was wrong, you see, I think that is wrong … Because when somebody isn't being rational, it takes a doctor to sit down for five minutes and decide what's happening here'. (Chris)

The majority of parents did not portray interactions with primary care services as effective partnerships. The language chosen to describe these interactions: 'a fight', 'a struggle', 'a battle' graphically illustrates the way these interactions were experienced. For these 'battling' parents, services appeared to contribute to strain in their parenting roles.

Analysis revealed that many of the parents perceived that services could not be trusted to ensure an optimal outcome; thus, parents felt they needed to be vigilant in ensuring the system worked for their son or daughter.

3.2 Lack of information

Parents reported that healthcare professionals failed to share information with them, virtually ignoring them as the son or daughter's main support. Exclusion and a lack of information reinforced parent caregivers' feelings of isolation and left them feeling detached. Kate sums it up when stating:

'*I think from he [son] went into [unit] we are like outsiders, you're not kept in the loop, well that's how I feel anyway, you're not involved in anything, you're not kept really up to date with what's going on'.* (Kate)

Most participants were clear about what would help them: a more integrated approach with good communication channels between the professionals and themselves. Not surprisingly, the accessibility of the forensic care setting was an important factor that negatively impacted parents' involvement and contributed to feelings of exclusion.

'Before she went to [unit] when she was in [unit] and all, there was times when the staff couldn't manage her because she was real weepy, em, and even if it was at night he [husband] wouldn't have been happy not to go. He would have sat with her and had a wee word … always got her round. Then she went to bed happy, and it was happy all round 'coz staff couldn't manage her … he [husband] was able to control the situation and there she went and got rid of whatever it was and he would have had her laughing and joking. But you can't do that in (unit) so we miss that part'. (Tessa)

Parents raised issues about the way mental health professionals interacted with them. The potential for a 'them' and 'us' perspective to exist is illustrated by Chris's emphatic remarks in relation to the distancing professional attitude he was met with during appointments with his daughter Claire's psychiatrist. Parents felt that they were being left alone with their experience and interpreted the responses of professionals as uncaring.

'It's a thing that I have tried to describe to Doctor [name] this very thing. But unless you're in this position on this side of the equation, you'd never understand what it's about. Do you know what I mean? Doctor [name] can have PhDs to fill this room … But he doesn't know how I feel. Never will … And when I try to explain 'til him he goes "Yeah Yeah, Oh. Yes, yes" … That's it'. (Chris)

Parents wished to be able to talk to someone who understood what their life was like. Extracts like the one above from Chris highlights the overwhelming sense of isolation experienced by parents who feel that there is much room for improvement in terms of the support they are offered.

Family members wanted to be treated as a resource. Parents emphasized knowing their son or daughter better than the mental health professionals who care for them.

'I know as soon as I see her face walking up the corridor I know if we are going to have a good visit or not … I mean I read the signs because I know my daughter, I know her better than anybody, and I can see by her face, I know when things aren't right quicker than the staff would, you know what I mean, so when I see her coming up, I know by the way she walks or her face that something is in the breeze'. (Tessa)

Parents also described recognizing patterns of emotions/ behaviours and how these recurred over time.

'I said to the wife a good while ago about this, it's like a cycle and I don't know if they [unit staff] see it … she goes through a period of elation … of nastiness and violence … she'll sit on a visit and use foul language talk about things that she can visibly see is upsetting me, I don't like that sort of stuff …. I can see all these and … when one of them happens I'll say to the wife "We went through this here before do you remember?" … "Next week she's going to be such and such" … and true enough, she'll change to something else, you know … it's a thing where, if we notice anything strange we would say to the staff when Claire goes back [to the ward] …. she was saying …. or planning to …. and put them ones aware of the situation, that's as far as we can take it'. (Chris)

Their caring seemed connected to their attentiveness to their child's needs both now and in the future. There was also a hope that the information they passed on would be used by health professionals to make better and more informed treatment decisions for their son or daughter.

Theme 4

"A very sad fact of life"- caring with no end in sight

This theme incorporates parents' feelings about diagnosis, parents' views of the condition of their adult child experiencing mental health difficulties past and present, as well as parents' thoughts and feelings concerning their child's future. A key issue for parents with a relative diagnosed with mental illness was being able to put a name to the behaviours. The diagnosis of a mental health problem confirmed parental intuition that something wasn't 'right' and completed their search for an answer. Nevertheless, the diagnosis of mental disorder brought grief and sorrow. A critical element of the meaning of informal caregiving was the search for the 'essence' of the son or daughter unaffected/unchanged by the mental distress. Parents were deeply committed to looking after their child in the secure unit and doing for him or her whatever was necessary. The future was viewed with a combination of hope, uncertainty and as 'never ending'. The super-ordinate theme "a very sad fact of life"- caring with no end in sight, contains five sub-ordinate themes 'getting a diagnosis', 'facing change and loss' 'staying connected' 'bearing the burden' and 'hoping for a better life'.

4.1 getting a diagnosis

After living for years in a kind of emotional limbo, it was comforting for some parents to have a name for their child's difficulties. The diagnosis explained the troubling behaviour and also gave hope that Doctors could provide help and support.

'Em to be quite honest with you, I was actually relieved that someone could say to me this is what is wrong with your daughter … and you know, this is the reasons why your daughter is doing what she is doing … because it is very difficult to watch your daughter … it took four years to diagnose her from that stage, and all the while she was getting more and more and more

ill … and I know now that her diagnosis has changed, but to me, back then, being told that she was schizophrenic made total sense to me … because she had everything that there was to make that up'. (Alice)

For other parents in the study, the knowledge that their child was suffering from a mental health problem was narrated as being a shock, accompanied with feelings of confusion, resulting in many more questions than answers.

'I hadn't a clue what it was, and when I heard paranoid schizophrenia, I … Is this curable? Will he be through this all his life? Will he be alright? Will he … I didn't know 'coz I never went through anything like that before' (Adrian)

Distress was the most frequently expressed emotion reported by the carers. The distress encompassed such mixed feelings as anger, disappointment, and frustration.

The following extract from an interview with Kate evidences a parent's frustration that assessment did not happen earlier.

'I'm terrified when I, when I read it … actually I wasn't told, I read it. I got the report and my first reaction was I cried … my second reaction was … I was angry … because I had fought so long for help and nobody, NOBODY was listening. Nobody … and I couldn't get help out there whatsoever …. so when it came to the bit where he [son] was cutting into himself thinking I had wires attached to the back of his head, well what … so yes, my first thing was to let it go so long … and that's what he's got'. [tearful] (Kate)

Chris reported feelings of grief and a sense of helplessness as he was unable to help his daughter.

'My job is to keep a home and a wife, and look after the family. I can't look after Claire. I can do nothing to get her out of this situation. Aye, a year, two years ago, a son of mine over there had some paramilitary types round the door blah, blah, blah…. I put on a coat and went and seen him. I know men who know men, and sorted the problem. Got rid of them. I can't do that for Claire … I can't put on my coat and go and sort this out and say "Right. C'mon you. Home!" … It doesn't go away ... that's it'. [tearful] (Chris)

4.2 Facing change and loss

Emphasised within this sub-theme are parents' perceptions that their adult child's mental health problems had resulted in them becoming a very different person. This included a loss of positive aspects of their character and loss of a sense of connection with the family member.

'There is times I go down there I think John is numb. Like he's on a different plane. Sometimes, you can't … your talking 'til him and he's not there ... I went to give him a hug whenever we were leaving like "Here's your hug" and you would near think there is no feeling there … I had ten, a thousand times more, you know, affection, walking out and leaving him'. (Thomas)

Parents compared their adult children now to their former selves to assess how much change had occurred.

'She has changed so completely; you know it's a terrible bad illness … Well, for a start her looks … and em, her mind the way it is …. with this fantasy business … she had a brilliant life and maybe that's why you notice it so much because you know, as I said ... she had a lovely life, she had a lovely lot of friends, she had a lovely personality, she was never nasty, she was just a nice person to know'. (Tessa)

4.3 Staying connected

Despite narrated experiences of the son or daughter as being changed, a core part of self not influenced by changes was observed. Caregiving meant understanding the importance of staying connected to their son or daughter in the secure unit and not to lose sight of the basic essence or identity of the individual.

'To me it's the same, and that doesn't make sense, but to me it's the same. When Claire was at school and a child, she was my daughter, and always would be my daughter. When she took ill she was still my daughter, and needed more attention than previous to that. Now she's even more ill, we are still there ... the only change, she has become ill, but the rest of Claire is still Claire'. (Chris)

The following extract from Alice demonstrates the strong bonds that exist between parents and their children and the sense of reciprocity within the parent- child relationship.

'In the main my relationship with Jen would be quite good … but then again, we go from really great em … to not so good. But I do know one hundred per cent that I am the most important person in her life … it's the same the other way round, you know'. [tearful] (Alice)

Parents used a number of coping strategies and drew strength from their sense of responsibility as parents and out of love for their son or daughter.

'We were always like a close family and even through all the abuse and all that we've had from her because of her illness…we don't like missing visits, because we know then it puts a distance and then it's like meeting strangers and we don't want that to happen … so we always try to, you know, be friendly with her and laugh and joke and all this. We try to keep her close'. (Tessa)

4.4 Bearing the burden

Bearing the burden means dealing with feelings of responsibility and constant worry and uncertainty about what life in the future will be like for the son or daughter with a diagnosis of mental illness.

The example below conveys the sense of sorrow that participants' experienced and reflects a belief that the relative is unlikely to return to their former self, bringing up new worries in relation to the perceived permanency of caregiving.

'Well … this stretch she has been in constant now for seventeen years … She was out previous to that for a couple of months. She was in (unit) for a year. Before that she had been in (unit) … In the last five years or so I've realised it's over …Claire is going to be a patient for the rest of her life. It's a very sad fact of life … but it is a fact of life. The dream has ended.' [tearful] (Chris)

Fears of uncertainty about the future were exacerbated by the unpredictability of the illness and a perceived fear that their adult child will have difficulty managing without their support:

'We are both ill and none of us know the minute we are not going to be here, and there's going to be a big change because we can't see anybody going up and looking after her … Now she does have two brothers, the younger one says "Do you think I would, you know, miss? … But he's just meaning well … it will never be the same as what we do. They [siblings] might decide to go once a year, or twice a year or whatever … if they remember they have a sister, so you know, we just struggle like that'. (Tessa)

4.5 Hoping for a better life

Hope was generally seen as essential by caregivers in them coping with the many challenges and struggles they faced and as a motivational force for the recovery process. Adrian described seeing signs of his son's behaviour changing for the better as providing him with hope.

'You can have a conversation with him now, whereas I went for years and never got a conversation out of Patrick … went for years, and I thought it was great because I even said to (wife) I'm delighted wae him'. (Adrian)

Thomas described his sense of hope as continually motivating him in providing care, without which his role as a caregiver would have no purpose.

'If I started to think about John, more than likely I wouldn't go down to see him. So you have hope for him. That's the only reason I go down and see him … If I started to feel pity and sorry for him, I would not go down and see him. So aye, if I didn't think that there was hope for him I wouldn't be there'. (Thomas)

In terms of the nature and focus of the hopes held by caregivers, both general and specific hopes were described. Adrian described his specific hopes being that his son will leave the secure unit with the ability to control difficulties related to his mental health and live an independent life.

'We want him to get out and, as I say, it's one goal for us him getting out and coming in here and saying "Alright mammy, right I'm going here and I'm going there and I'll give you a ring when I get home" and him ringing us when he gets home or whatever and whatever and "Everything alright son?" "Aye, dead on" … that's what we want'. (Adrian)

Whilst the narratives displayed hope as a sustaining force to seek ways to improve life for the son or daughter, they also revealed the struggle to remain hopeful.

Alice expressed guarded hoped for the future of her daughter Jen:

'Jen will never ever live independently … she's been in hospital for too long. She's institutionalised … and you know, in some ways I'm fine with that, em … but what I would like for her is… if she was well enough…where she would live in assisted housing…that would be nice for her. But then in saying that, the mind has to be right to be able to make choices, you know … maybe more so in Jen's case you know … but as I say as time moves on, and you kind of wonder is that going to be possible'. (Alice)

Within caregivers' descriptions of their hopes, there was also an awareness that expectation is inseparable from the risk of disappointment. Many identified that the role had become their whole life, with no anticipated respite now or in the future.

Now she's even more ill, we are still there, we are still … every day [ ] we'll do the best we can for as long as we are here. People should be made aware (you) don't build you're hopes too high with this illness, in some cases this illness will go on for a life time. I found it, annoying is the wrong word … I found it very unacceptable that I wasn't clever enough to work it out at the start'. (Chris)

Discussion

This study has researched the experience of six parents who support adult children diagnosed with a mental illness receiving compulsory treatment in a medium secure forensic unit, and additionally enquired how involved these informal carers felt in the treatment of their relative in secure care, as well as seeking to explain what continued family involvement means for parents in this context. In this final section, findings are discussed in relation to similarities with other research cited in the introduction as well as the unique contribution of the study to extend understanding of the lived experience of forensic caregivers. The aim is to draw together key themes across all of the data, and to consider the findings in terms of how to achieve fundamental change for how parent carers are supported and guided through very difficult experiences.

Meaning of forensic caregiving

The meaning of parental care for a son or daughter with a mental health problem living in a forensic setting was illuminated in the themes "something's not right"- onset of mental distress; "going through hell"- experiences of violence and entering secure services; "it's a terrible battle"- relating with professionals; and "a very sad fact of life"- caring with no end in sight.

Parents' experiences were grounded in a changed temporal world. The onset of mental health difficulties was narrated as a fateful event that transformed the course of the family.

Family caregivers reported that they did not know whom to contact to ask for help when their child was becoming unwell and described these

situations as very stressful, as they had to look after a son or daughter who was unwell, at the same time as trying to find out how to get help. Often they were directed from one service to another, without being given effective guidance.

Family caregivers often believed that their relative was more unwell than judged by the clinicians and that the family member experiencing mental distress needed more support from professionals and services than was being offered.

This disagreement with the health professional's assessment regarding the level of professional support required contributed to the burden of care experienced by parent carers. More specifically, family caregivers commonly believed that their son or daughter should have been admitted to a specialist unit earlier. Family caregivers often thought that the delay in response of services contributed to the deterioration of their relative's condition.

Some thought that services focused on responding to adverse events rather than on preventing them and therefore perceived services as reactive rather than proactive.

The most common emotional response to admission to the regional medium secure unit was relief. The relief appeared associated with the burden that family caregivers had experienced before the admission.

Endless parenting continued to be a force in these parents' lives though they did not serve as primary caregivers. Parental caregiving emerged as a life-long effort to help and support the son or daughter suffering from mental illness living in a forensic setting.

Findings suggest that perseverance in the informal caregiving role is based on devotion to the adult son or daughter. These parents at no point thought of abdicating their caregiving role or letting professionals assume responsibility for the total care of the adult child.

The caring role could be stressful and affect carers physical and mental health. Being a forensic carer demands years of resilience, coping with visiting a prison-like environment; trying to understand complex legal and medical rules and regulations; and struggling to come to terms with the strange new restricted world that parents entered without any choice or easy way out.

Stemming from the study results, a pathway model of informal caregiving by parents of adult children with mental distress living in a forensic setting was developed (figure 2). Analysis identified the quality of the parent-child relationship, indicated by communication, as critical in the initial awareness phase. Difficulties in communication tended to prevent or inhibit parents from noticing initial signs and changes. Family history of mental illness may have allowed some parents to recognise early signs of mental distress in their children. Some parents became aware of their children's problems by observing more unusual behaviours and severe symptoms that would warrant help seeking. Parents described being alarmed by specific symptoms including command hallucinations to harm self or others, aggression towards family members, social withdrawal, functional impairments and suicidal ideation. Parents promptly began help seeking after recognising severe symptoms. Parents listed barriers in seeking and securing help. Parents reported a lack of knowledge of available resources. After taking the first step to seek help, some parents encountered situations

such as insufficient support, resulting in them feeling alone and overburdened. Parents did not appreciate professionals who did not communicate or partner with them.

Figure 2. A pathway model of informal caregiving by parents of adult children with mental distress living in a forensic setting

Stage	Phase	Critical factors
Contemplation	*Initial awareness*	Parent-child relationship Family history of mental health difficulties Observing unusual behaviour and symptoms vs. going unrecognised [by parent], being informed [by child]
	Recognising severity	Observed changes: functional decline, irritability, mood lability, social withdrawal, aggression towards family members. Visibility and regularity of symptoms Perceived burden Attributions: drug induced, stress/vulnerability, unknown, misattribution of problem behaviours deriving from another condition, a passing developmental phase
	Considering options	Parental decision Others [primary care providers] deem help necessary Views about personal autonomy of adult child
Action	*Crisis*	Dangerous incident involving either actual or potential harm to individual and/or others
	Help seeking intention	Parent attitudes to services
	Securing help	Child's attributes Child's attitude to services Service focused barriers: child needs to be convincingly mentally unwell when they present to clinicians, insufficient mental health services that can meet the needs of the person, inadequate service responsiveness in crisis situations (after hours/ weekends) Carer focused barriers: limitations in parents' knowledge of specialist support services [existence and location], unfamiliarity about how to negotiate access to services
Maintenance	*Service appraisal*	Quantity and quality of care: competence of staff, environment Individuality: respect for individual needs, confidentiality, care Partnership: involvement in decision making, accessibility, giving and receiving information

Comparison to the literature

The study findings are similar to those described at the beginning of this dissertation and within the introduction section of this chapter, which highlighted forms of parental caregiving, the impact of the diagnosis on the parental experience, and the changing nature of parental roles over the course of the child's presenting complaints. Regarding forms of caregiving, parents in the current study, like parents in Chesla's (1991) study who practiced engaged care, were actively involved with their child. They tried to understand their child's world, worked to engage their child in the real world, and were interested in fostering their child's self-esteem. They also affirmed their child's strengths. Like the parents in Chesla's (1991) study who used managed care, it was important to the parents in the current study to inform themselves about the mental health diagnosis given to their son or daughter.

As with the study participants in Tuck et al. (1997) parents in the current study became frustrated with the inability of mental health professionals to identify the problem and were greatly impacted by the diagnosis. Similar to the findings of Tuck et al. (1997) and Milliken (2001) the parents in the current study experienced devastation, uncertainty, as well as periods of hope and despair as they struggled to make sense of their experience. Parents in the current study experienced frustration with the mental health system as they tried to protect and find help for their child, particularly in crisis situations, a finding similar to the parents interviewed in the study by Milliken (2001).

As in the current study, feelings of grief and loss have been articulated by parents of patients diagnosed with schizophrenia in a forensic setting (Ferriter & Huband, 2003). It is not clear whether there is a different quality of grief among parents of sons and daughters detained within forensic services compared with those in the more general psychiatric population. Nevertheless, aspects of grief as reported in the general literature are reflected in the accounts of parents within this study.

Consistent with other studies in the general psychiatric population (Ozgul, 2004) parents described a feeling of powerlessness when they realised that they were unable to halt their family member's deterioration, which led to a process of resignation.

The findings by Jankovic et al. (2011) that family caregivers frequently feel a sense of relief in response to their family member's compulsory hospital admission is similar to experiences reported by forensic caregivers in this study and may be contextually specific for situations such as this, where forensic carers reported facing verbal abuse and threats of aggression from their son or daughter on a more or less daily basis. Jankovic et al. (2011) state patients who are involuntarily admitted to hospital commonly have high symptom levels and challenging behaviour with risks to themselves or others before admission. In such a context, caregivers may experience high levels of burden, and therefore appreciate more the treatment provided in a mental health hospital, or in this case, a forensic mental health unit.

The findings that mental health services are perceived as poor at proactive involvement and instead mainly responding to crisis, confirms results of a study by Jones et al. (2009) who interviewed patients and family caregivers

and found that the crisis-led nature of services meant that those patients who were relatively stable, or did not display signs of potential risk to self or others felt isolated, and on the periphery of service delivery.

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

Parents described wanting their adult children to be independent but recognised that he or she may always require their support, consistent with previous findings in the general psychiatric population (Wane et al., 2009; Hanson, 1993).

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

Parents in this specific forensic population had described being unable to get help for their relative until a crisis had occurred. MacInnes (2000) also highlighted the poor service that parents perceived their child received from mental health services before they seriously offended resulting in compulsory detention in a forensic mental health unit. Other studies in the general psychiatric population have highlighted struggles that many families have in trying to get services to take notice of their mentally ill member, even in an emergency situation (Askey et al., 2009; Carter, 2011; Gray et al., 2010; Wane et al., 2009; Wynaden, 2007).

Parents in the current study described not having a common language with professionals which hindered effective communication with them, consistent with findings in the general psychiatric population in a study by Ridley et al., (2010). Drapalski et al. (2009) noted that people who do not have experience of the general psychiatric mental health system may need information to successfully navigate it.

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

Implications for practice

There are a number of key implications for parent caregivers and health professionals working in secure services.

Greater awareness is needed of the contribution, experience and difficulties parent caregivers face accessing services for the first time.

The period following diagnosis is a key point at which parents need information and support. Health professionals need to acknowledge the emotional challenges that parents face at that time. Therefore, a sensitive, family centred approach would be appropriate. The diagnosis should be imparted by personnel specifically trained in family intervention/family centred approaches.

Staff in forensic mental health services need to appreciate that parent carers often need help and support when their relative moves between secure services, as well as on admission from prison or general psychiatric services. Preparation and support prior to the first visit to any secure unit, for example, may be very valuable for parents with lived experience of caregiving for an adult child with mental health difficulties and offending background.

The biggest challenge identified by carers was in getting the support they wanted from services to ensure they were meaningfully involved in the care of their relative. Despite some positive experiences, many felt they were not listened to by clinical teams, and certainly did not feel they had been treated as partners in caring for their son or daughter. Carers in this study did not always feel respected or adequately informed, including about forensic mental health services and their rights as family caregivers.

These findings suggest a need for forensic mental health services to reconsider the mechanisms in place for inviting parent carers to formal reviews and meetings, and the extent to which they are supported to attend.

Various initiatives on forensic care pathways make the case for more systematic involvement of carers, linking this with risk management, discharge planning and formal carer assessments (Kelly et al, 2002; Kennedy, 2002; Gill et al, 2010). The *Triangle of Care* is in use in English high secure settings to encourage carer recognition and involvement.

As highlighted in the literature (Ferriter & Huband, 2003; Hughes & Hughes 2000; McKeown & McCann, 1995) this study found that carers can experience stress as a result of the forbidding nature of visiting secure settings, and/or because of the emotionally tense nature of meeting with their relative under forensic mental health services. There is a clear case for focused support for carers around visits to assist them to make more rewarding contact with their son or daughter and also to build trust with staff. Consultants and managers have a pivotal role to play to ensure the right culture is created to support positive, open (non-defensive) relationships with forensic carers.

It is paramount that the caring profession remain flexible in the support provided to parents and recognise that the needs of the families may vary over the course of time.

Suggestions for future research

Research on families' lived experience of their relative's mental health difficulties and professional care could be progressed to consider how the parents' experiences fit with other family member's perspectives. Taking a systemic perspective could help elucidate the relational processes within these families, thus broadening knowledge about communication, and family resources in this context. Future studies that are aimed directly at siblings of adult children living in a forensic setting being cared for by professionals, are recommended to compare parental observations with siblings' phenomenological accounts of lived experience.

Methodological considerations

The methodological approach chosen for this study fitted with the research aims, allowing for a set of rich, complex and rigorous findings about parents' experiences. As IPA is an idiographic approach which does not seek to find definitive and positivist answers, it is not possible to generalise the findings to all parents supporting a son or daughter in forensic (secure) mental health services. Instead, IPA aims to contribute to a gradually developing knowledge base, resonating with professional and personal experiences and shedding light on the broader context (Smith & Osborn, 2008).

The sample consisted of an equal number of male and female carers who were of Caucasian ethnicity. A limitation of the study is the absence of Black and Minority Ethnic participants. It is possible that being a parent of an adult child with mental illness being looked after by professionals in a forensic setting is experienced differently across cultures and different religious backgrounds. Research shows that individuals from Black and

Minority Ethnic backgrounds appraise the caregiving situation differently to white British family carers (Janevic & Connell, 2001).

Eight people met the criteria and agreed to take part in an interview. Heavy snowfall prevented one interview from taking place, and after another meeting date had been arranged, the individual then changed their mind and withdrew from the study. Withdrawal of service user consent meant that another parent could no longer be included in the research. The study is therefore based on the experiences of six parents. This number is in line with Smith et al. (2009) who advise that four to ten participant interviews are sufficient to gain richness of data and allow for similarities and differences to be examined. Whilst it is acknowledged that the sample size of six is at the lower end of what would be considered acceptable for the methodology, because the primary concern of IPA is with a detailed account of individual experience, it is argued that intensive focus on the six parent participants has achieved greater insight into the lived experiences of these individuals.

It is acknowledged that the sample used in this study was self-selected and might have been biased, with a higher motivation of discontent caregivers consenting to participate and communicate their views. Those family members who chose to participate often explicitly expressed dissatisfaction with mental health professionals and services. These experiences may be reflective of the specific sample of individuals who volunteered, which should be borne in mind. Other parents, if they had participated in this study, may have had different experiences to the kind reported here. It may be that parents who were more satisfied with the professional care of their son or daughter perhaps would have been less eager to participate, not

feeling the same need for emotional ventilation apparent in the sample of parents described here.

Another limitation of the study is that only caregivers of patients who gave consent could have been approached and asked to participate in the study. One can only speculate as to whether patients and caregivers with difficult relationships were less likely to participate in the research. Parents of sons or daughters who did not take part in the study might have different experiences from those described here.

In keeping with the general purpose of IPA, the semi-structured interview was only used as a guide to generate potential topics of interest. This gave participants control over the direction of the interview and parents were free to discuss issues they felt important. This may go some way to help explain why there was little discussion from parents on offending in the context of mental illness, and use of violence, or acts of aggression by the adult son or daughter detained in the forensic medium secure unit. Additionally, it can be inferred that participants may have been wanting to defend against painful thoughts and feelings around aggression or offending and so glided over these topics during interview. Furthermore, it is possible that the information imparted to the researcher may have been restricted by their concerns about how this knowledge would be used and who it would be shared with. Conducting a second, follow up interview with individual parents, although not part of the current study, may have enabled participants to speak more openly about topics, in particular, thoughts and feelings about the offending background of their son or daughter, less evident in the present study.

Additionally, one of the interviews took place with a mother and father present together (at the request of the couple). Although this may have certain advantages as parents remember together and talk about common experiences, the main disadvantage of this might be that either one of the participants may have been reluctant to discuss certain issues in front of the other person. An individual interview with each parent in this pairing would have allowed each person full scope without influence from their spouse, and had this been done, it is possible that two individual interviews would have produced different or perhaps even richer data.

In order to gain an in-depth understanding of the studied phenomenon, IPA requires a homogenous sample. The sample was relatively homogenous as parents in this study shared a common experience of having an adult child being looked after by professionals in a specific legal and service context, although the combination of mothers and fathers in the sample (where relationships can be different) is recognised as a source of heterogeneity, and is thus a limitation.

The interviews were based on individual participant's recall of events and therefore recall bias and discrepancies are likely to occur and present problems in terms of accuracy and reliability. That being said, the accounts of family caregivers resonate with one another and with the results of other qualitative studies, increasing their claim to credibility.

There are implicit limitations arising from the interpretative nature of the study. Although the author strived to ensure trustworthiness and transparency throughout all stages of analysis and interpretation, it is

acknowledged that what are presented are one's own interpretations, and others may have found something else salient.

Conclusion

This study has addressed an important clinical forensic issue that has rarely been explored in research.

The findings from this study demonstrate that being a parent carer to a family member living in a forensic mental health setting is a complex and challenging role.

Parents welcomed the opportunity this study represented to talk about their experiences, stating that they had not been afforded a chance to speak and work through these experiences either in informal conversations or in a more therapeutic relationship.

From the parents' perspective, the most important change that can be made is for staff to be 'carer aware'; to perceive parent carers as important to engage with, with needs of their own, as effective allies in a triangle of care, and pay due attention to the crucial importance of forging warm, respectful and constructive relationships with family members.

Many parents described 'battling' the service system. Of central importance appears to be reinforcing parental identities, respectfully acknowledging their perspectives and experiences and responding to parents' needs at difficult times during the period of mental health caregiving. Such efforts may foster positive interactions with service providers, meaning that these parents no longer feel they have to battle to get their needs met, and, by

maximising the positive contribution that carers can bring, lead to an improvement in service user care and safety.

Recommendations

The following recommendations are based upon the findings of this study and are directed at policy makers and practitioners wishing to implement best practice.

- There should be named staff as a point of contact for new carers.
- Forensic mental health services should give extra information, advice and support to carers when the person they support moves to a different facility.
- Parent carers should have access to advocacy.
- Forensic carers should be involved in support planning and reviews.
- Forensic mental health services should hold regular events for informal carers including open days on secure units.
- All forensic mental health services should support a regular carer support group run by the unit, the voluntary sector or carers themselves.

Chapter 3: CASE STUDY

Individual assessment and intervention of an adolescent sex offender and his family members.

Abstract

This case study is in two separate but interconnected parts. The first section presents the case of Jack who was admitted to a sex offender assessment and treatment unit for persons with a learning disability, having been convicted of the rape of a minor. Jack engaged in weekly psychology sessions between January and August 2012 which aimed to provide insight into any areas of risk and need that required treatment. In the second section of the case study, I describe a one- off coinciding project, in which three family carers of the adolescent sex offender client, were provided with information and support sessions developed to foster relations between the clinical team and family and to share information between family, service user, and team in a structured and contained way. Jack's progress and that of his family is described, along with personal reflections on this joint undertaking which was a first of its kind for the sex offender unit. The evaluation is descriptive in nature and based on feedback gathered from the four individuals directly involved, Jack and his family carers. Results suggest a family based approach to assessment and treatment can assist in decreasing denial for an adolescent sex offender, unify the family and encourage the family members to be a positive resource for one another. The implications of developing a partnership between family and staff means the strength of each combined leads to a better quality of life for the service user than is possible to provide separately. The project undertaken is an illustration of a process by which collaboration between staff and family is achieved.

Links between research project and case study

The empirical research is connected to the case study as it illustrates working with parents of forensic service users in practice. As has been described in detail in the systematic review and subsequent research project, families and carers of service users admitted to mental health inpatient facilities have often felt excluded from the caring process. Although more may need to be done to address the apparent shortfall in information for families, the series of appointments offered to a family of an adolescent sex offender and described in the second part of the case study, identify a mechanism that practitioners can use in partnering with carers and families. At the time I was on placement at the sex offender and treatment unit where this case study was carried out, there was no specific ward policy for the engagement of staff with service users' families and carers. Contact between them usually took the form of ad hoc conversations in public areas on the wards unless family members requested interviews with staff or made complaints. In these formal situations families or carers had only limited opportunities to explore areas of concern. The client I worked with was a first offender, who had never lived away from home. His parents and uncle were jointly involved in caregiving and were intent on continuing to do what they could to support the client following his admission. The family were very close-knit and reported that the upheaval of their son's conviction and the imposition of a hospital order, was unlike anything they had ever experienced. I hoped that by communicating with the client's family in a supportive, informative and caring way early on in the client's admission, his hospital experience and everyone's adjustment would be improved. Within the offender rehabilitation literature there is

support for developing interventions geared towards promoting the inclusion and involvement of family and friends. By way of example, the Good Lives Model of offender rehabilitation (Ward & Maruna, 2007) identifies relatedness, which is defined as the development of close caring relationships with an intimate partner, family members and close friends, as a primary good for offender populations. In addition, the HCR-20 version 2 and version 3 (Douglas, Hart, Webster & Belfrage, 2013; Webster, Douglas, Eaves & Hart, 1997) risk assessment tool includes the examination of family relations (e.g. lack of personal support) for mapping out risk management strategies in an offender's current and potential future environments. Therefore, family- based interventions would seem consistent with this offender rehabilitation perspective, as well as being viewed as imperative to the wider recovery. While it is acknowledged that the current intervention did not meet the requirement set out by NICE guidelines regarding family therapy provision, being able to access some form of family therapy is particularly important to support family engagement, especially as research findings suggest that the majority of mentally disordered offenders have high contact with their relatives (72 %) and that families are frequently involved (56 %) in discharge planning (Absalom, McGovern, Gooding & Tarrier, 2010). The carer support sessions appeared to be an acceptable way to fill the void between family and forensic mental health services in a useful and meaningful way.

Definitions

For the purposes of this case study, the term 'learning disability' will be used in accordance with the current UK Government definition: "Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development." (Department of Health, 2001) Intellectual impairment is conventionally assessed psychometrically and corresponds to an Intelligence Quotient (IQ) of 69 or less.

Barbaree and Marshall (2006) proposed that an adolescent sex offender is a person who has been convicted of sexual offence (for example, rape or forcible sexual contact) and is old enough to be held criminally responsible for the crime. In Britain the age of criminal responsibility is 10 years and this age is consequently used as the lower age bound for the group in both research and in clinical practice (Masson & Erooga, 1999). The most commonly used upper age bound seems to be set at the age of majority, typically 18 years.

Theory and aetiology

The most commonly presented theoretical models were developed on the basis of sexually offending adults and then adapted for the understanding of sexually offending youth. Some of the more informative theories in relation to the current case study are briefly presented below.

Finkelhor's four preconditions to sexual offending (Finkelhor, 1984).

The Finkelhor (1984) Precondition Model is described as one of the most promising aetiological theories for use in the rehabilitation of sexual offenders (Ward & Beech, 2006). It has had an important role in both research and practice (Ward & Hudson, 2001) and has been used as a framework for understanding aspects of male offending (e.g. Duff & Willis, 2006). It was developed through reviewing the literature of child sexual abuse and focused upon work with adult offenders. However, if the model is appropriately adapted it may help to make sense of other forms of abuse and different types of offenders, including adolescents (Hoghughi, 1997).

The model is based on research suggesting that in order for sexual offences to occur, the offender must pass through four planning stages:

The first precondition is 'motivation to sexually abuse' which encompasses three further factors: 1) emotional congruence, 2) sexual arousal, and 3) blockage.

1) Emotional congruence is the non-sexual motivation of sexual abuse, characterised by the congruent relationship between the adult's emotional needs and the child's characteristics. This idea is based on research that characterises sex offenders as having an arrested psychological development, which is more similar to that of a child than to that of an age matched peer. 2) Sexual arousal is a component of motivation to sexually abuse and is typically described in a social-learning framework. This factor accounts for the pattern of development of arousal to children as sexual objects and whilst this process may be more entrenched in adults, it may be key in understanding the development of sexually abusive behaviour in

adolescents. 3) Blockage is the idea of exploring why some fail to have their sexual and emotional needs met in adult relationships.

The second precondition is 'overcoming internal inhibitions' where internal inhibitors are individual and social/cultural factors which may serve to prevent an individual from committing a sexual offence. Finkelhor (1984) argues that many people may have an inappropriate sexual interest in children and are motivated to commit a sexual offence but would never do so as they are inhibited by social rules. Inhibition at the individual level encompasses the values and beliefs the individual holds about themself, the role of women and children, and the consequences of committing a sexual act. Individuals are said to overcome this individual inhibition with alcohol or other substance misuse and through the use of cognitive distortion, which is essentially a permission granting process to engage in sexually abusive behaviour. The social and cultural factors which enable 'disinhibition' include a social tolerance of sexual interest in children, weak punishment for those convicted of sexually abusive behaviour, patriarchal ideologies, social tolerance for deviance committed when intoxicated and child pornography.

The third precondition is 'overcoming external inhibition' which are said to be the environmental factors which protect the child. The main external inhibition according to Finkelhor (1984) is adequate supervision of the child and presence of a parental figure, particularly the mother, which is said to help protect the child from potentially harmful/risky situations.

The final precondition is 'overcoming resistance of the child', where specific children are targeted and 'groomed' for engagement in abusive acts, as

they are deemed appropriate to the individual. Finkelhor (1984) argues that this is a complex precondition to abuse as it involves many subtle aspects of the child's behaviour and personality. Abusers might introduce victims to sexual stimuli in a graduated way, encouraging sexual curiosity and exploration by the child. They might use force or threats of dire consequences to the child or another family member, in order to gain the victim's cooperation.

Ward and Hudson's (2001) critique of the model highlighted a number of weaknesses, including a lack of attention to developmental factors, as well as a lack of detail concerning the way the psychological vulnerability factors are specifically linked to the perpetration of sexually abusive behaviours.

However, the model is commended for the way it relates a broad range of causal factors to the offence process, providing a useful framework for therapists (Ward & Hudson, 2001). Indeed, it was selected for use in the present case study based on this merit, as the model explores specific details of the offending behaviour that can inform future risk management strategies for the individual. The application of the model also aims to increase the individual's awareness of the offending behaviour in detail, establish acceptance of the premeditated nature of sexual offending, reduce denial and increase empathy for the victim. The precondition model was also selected for use as it prioritizes the impact of external and environmental factors in the understanding of the offence process, unlike the Quadripartite Model (Hall & Hirschman, 1991). Furthermore, according to Howells (1994) the model has face validity and directs the clinician's attention to important therapeutic and assessment targets- for example,

cognitive distortions that the offender may hold and the effects of their actions- features that were considered to be relevant in this case study.

Marshall and Barbaree's Integrated Theory (Marshall & Barbaree, 1990; Marshall & Marshall, 2000).

Marshall and Barbaree (1990) present an influential model which concerns the development of sexually abusive behaviour. According to their model, an essential developmental task for adolescent males is to learn to discriminate between aggressive and sexual impulses. Following this, they need to differentiate their responses to these impulses, and control their aggressive tendencies during sexual experiences. Marshall and Barbaree (1990) contend that this is made more complicated during adolescence due to the increase in male sex hormones and steroids. This theory emphasises the development aspect, and examines behavioural templates that are required in childhood and particularly in adolescence. According to Marshall and Barbaree (1990) some men have a strong predisposition to sexually abuse, while others display a high level of resilience against sexually abusive behaviour. They posit that the factors that constitute resilience, to be those abilities, skills, attitudes, preferences, beliefs and values that enable an individual to resist the urge to offend. The Integrated Theory identifies biological processes, developmental experiences, cultural norms and values about sex and situational factors, as important contributors that interact to result in sexual abuse.

The development of vulnerability to sexually abuse

Marshall and Barbaree (1990) identify early childhood experiences as critical to the formation of a template for interpersonal skills, necessary to successfully negotiate the transition to adulthood through adolescence.

Children who are neglected or abused will develop a view of themselves as unworthy and find it difficult to trust others. Their attachments to their caregivers and parents are insecure and they have difficulties with emotional regulation, problem solving, low-esteem, poor judgement, impulsivity and self-efficacy. According to Marshall and Barbaree (1990) these children are likely to experience their parents and caregivers as emotionally unavailable and rejecting of them. These children would then avoid disclosing their thoughts and feelings to others and when distressed will tend to isolate themselves. This impedes their developing capacity to elicit support and comfort from others. As a result of this, their capacities to self-regulate and negotiate emotionally intimate relationships are impaired.

In the case of those who have experienced child sexual abuse, they are more likely to turn to masturbation, or sexually abusive behaviour to comfort, given their impaired and insecure attachments to others. Marshall and Barbaree (1990) also identify exposure to antisocial and misogynistic behaviour in the home as contributing to the development of these proclivities in the child. A child witnessing their mother being denigrated might consider women as inferior to men, or they might learn that intimate relationships are characterised by fear, anger and violence and are to be avoided. Children who are sexually abused could come to regard sexual contact between adults and children as mutually beneficial and normal, particularly if the abuse was pleasurable and occurred within the context of a 'caring' relationship.

Vulnerability and the challenge of adolescence

Marshall and Barbaree (1990) contend that the task of differentiating sexual and aggressive impulses is a particularly difficult one during puberty. They base this idea on the notion that the sexual and aggressive impulses use the same brain structures (hypothalamus, amygdala, septum and pre-optic area) involve similar endocrine hormones and neural networks, and result in a comparable sense of arousal. Thus, given the inculcated social norms of vulnerable adolescents, they would find it difficult to know whether they were sexually aroused or angry, or both simultaneously.

According to Marshall and Barbaree (1990) the templates formed in childhood set the stage for how the young person negotiates the challenging developmental task of adolescence. They posit that it is during this period that sexual preferences are acquired and sexual behaviour learned. Adolescents who have been subject to abusive experiences are less likely to successfully negotiate the challenge of managing their sexual urges created by the increase in male hormones at puberty. As these young people enter puberty lacking in interpersonal skills, self-confidence, and self-efficacy, they find it difficult to approach and engage potential sexual partners in an appropriate way that will facilitate relationship formation, and contribute to the sustainability of these relationships.

Vulnerable adolescents who have been abused as children lack a satisfactory template for sexually and emotionally intimate behaviour, they are more likely to withdraw from others, or behave inappropriately or abusively, depending on the nature of their earlier exposure. They also lack the self-confidence and social skills to cope with inevitable rejections, and they process their resultant negative emotional states and anger towards

women through aggressive, sadistic or deviant fantasy. These many in turn be reinforced through masturbatory activities. This could result in the maintenance or escalation of this behaviour. These masturbatory experiences might reinforce their dysfunctional template for relationships, or also become rehearsals for future sexual offences.

A critical aspect of Marshall and Barbaree's (1990) theory is that people meet a number of psychological and emotional needs through sexual behaviour. So, adolescents who feel emasculated by their lack of success at finding a sexual partner might achieve a sense of empowerment and self-esteem from deviant fantasies and sexually abusive behaviour.

Situational factors

The Integrated Theory contends that the aforementioned vulnerabilities interact with transitory environmental cues or circumstances to produce sexually abusive behaviour. According to Marshall and Barbaree (1990) these men who sexually abuse children might purposefully create or encourage the development of these circumstances. These situational disinhibitors include substance abuse, negative emotional states such as anger and anxiety, and the presence of stressors. Stressors include the loss of a relationship, social rejection and loneliness. Factors that appear to condone or encourage sexually abusive behaviour might also facilitate the overcoming of normal inhibitions. These factors include pornography, alienation from potential sexual partners and anonymity.

This theory has been evaluated as having empirical adequacy and external consistency, as it is both dynamic and complex. As a result, it is supported by and focused on, in multiple areas of research (Marshall, 1999; Smallbone

& Dadds, 1998; Ward, Polaschek & Beech, 2006). Marshall and Barbaree's (1990) model offers a developmental perspective on how people come to sexually abuse children. It is a sophisticated model that integrates biological, psychological, social, cultural and situational factors to account for child sexual abuse. As this model takes a developmental perspective it facilitates some understanding of how adolescents might sexually abuse. This model also identifies psychological vulnerabilities and resilience factors to sexual abuse. However, it does not account for how those with high self-esteem might commit a sexual offence (Ward, Polaschek & Beech, 2006). One of the deficits of the Integrated Theory is that it is a 'one size fits all' framework, based largely upon a retrospective view of men convicted of sexual offences. In addition, the Integrated Theory does not give an adequate account of how those who experience psychological distress as a result of being reared in an abusive family do not engage in sexually abusive behaviour (O'Reilly, 2004). Furthermore, it has been argued that the Integrated Theory places too much emphasis on impulsivity at the cost of understanding the beliefs underlying offenders' goas and values (Ward, Polaschek & Beech, 2006).

The Integrated Theory of Sexual Offending (ITSO; Ward and Beech, 2006)

The Integrated Theory of Sexual Offending brings together theories from three different levels; the multifactorial theories, the single-factor theories, and the offence process theories. Ward and Beech (2006) suggest that three sets of factors continuously interact; biological factors (genetic predispositions and brain development); ecological niche factors (social, cultural, and personal circumstances); and neuropsychological factors.

According to this theory, sexual offending occurs through the ongoing confluence of distal and proximal factors that interact in a dynamic way.

The Integrated Theory of Sexual Offending has been included in this case study because it emphasises the importance of developmental factors (genetic predispositions and early life experiences) in sexual offending and the authors have attempted to relate the theory to people with intellectual disability (Keeling, Rose & Beech, 2009). The ITSO helps highlight the factors that are relevant for the client's formulation in relation to his risk of sexual reoffending.

Biological Factors

This first factor highlights that individuals enter the world with various genetic advantages and disadvantages (Ward, Polaschek & Beech, 2005) and that genetic determinants may result in a pre-disposition to seek basic goods (Ward & Beech, 2006). For individuals with a learning disability, biological factors are likely to be pertinent due to the biological nature of inherited difficulties and developmental difficulties during pregnancy (Keeling, Rose & Beech, 2009) that likely predisposes these individuals to other combined difficulties, such as cognitive processes and dysfunctional motivation. The theory proposes that these combined difficulties (genetic, motivational and cognitive) lead an individual to meet their sexual needs in socially unacceptable ways via sexual offending (Ward & Beech, 2009)

The ecological niche

Ward et al. (2005) stated that the ecological factors are a combination of social, cultural and personal circumstances, as well as the physical environment. The ecological system places importance on both early developmental experiences (distal factors) and personal circumstances

(proximal factors). Ward & Beech (2006) suggest that it is possible that the major causal factors leading to sexual offending may lie within the ecological niche rather than with the person. As discussed previously, people with intellectual disabilities may be particularly vulnerable to poor developmental experiences (e.g. Baxter et al., 2000). According to the ITSO (Ward & Beech 2006), factors that may lead to poor developmental experiences, such as poor parenting, sexual and physical abuse, and limited social supports, may be important distal factors in the development of sexual offending behaviour. As regards to proximal factors, Lindsay (2005) discusses control theory (Hirschi, 1969). This theory relates to the learning of criminal behaviour through positive associations with negative influences and the development of self-control through appropriate learning. Specifically, Lindsay discusses that a lack of engagement with society, as a result of negative influences, may place someone at risk of offending. These proximal factors could be further exacerbated by the experience of stigmatization and social isolation for people with intellectual disabilities (Dagnan & Jahoda, 2006).

The psychological system

Ward, Polaschek and Beech (2005) hypothesised that impairment in both the biological and ecological systems could lead to a significant impact on an individual's psychological system. This system consists of *neurological functioning* with three interlocking neuropsychological systems.

1) The motivation/ emotional system is contained in the mid-brain limbic systems. It is the neuropsychological manifestation of maladaptive motivations and emotions, which are the product of an individual's

genetics, culture and personal experiences. Ward et al. (2005) proposed that early developmental experiences significantly affect the likelihood of forming maladaptive motivation and emotions, which create a vulnerability to seeking emotional gratification in inappropriate ways. As sexual offenders with intellectual disabilities may be particularly vulnerable to significant negative distal and proximal factors (e.g. poor developmental experiences, stigmatization), deficits in the motivation/ emotional system may be important features in the aetiology of sexual offending for this group.

2) The second system is the perceptual and memory system, which is where schemas or implicit theories (Ward & Hudson 2000) are stored. Problems in the perceptual and memory system can lead to maladaptive beliefs, attitudes and problematic interpretations of social encounters (Ward & Beech, 2006). Presence of maladaptive beliefs that are frequently available to guide information processing are likely to cause the activations of problematic goals and emotions, which in turn make it difficult for a person to effectively control their behaviour. These are formerly known as offence supportive cognitions (Thornton, 2002) and cognitive distortions (Abel et al., 1989). Cognitive distortions have been consistently identified and addressed in the treatment of sexual offenders with learning disability (Lindsay, 2005; Lindsay & Smith, 1998; Rose et al., 2002). Early maladaptive schemas which influence the development of problematic personality traits could be included in this system.
3) The action selection and control system relates to an individual's ability to formulate an action plan and achieve the related goals.

Problems in this area relate to self-regulation difficulties such as poor problem-solving and impulsivity and represent vulnerability to sexual offending (Ward & Beech, 2006). Keeling and Rose (2005) proposed that sexual offenders with learning disability would be more likely to offend via pathways characterised by poor self-regulation. However, further research is needed to clarify the relevance of the action selection and control factor for this population.

Ward and Beech (2006) suggested that the ITSO provides a conceptual framework to unify other theories and generate novel research hypotheses. One strength of this theory is that it has strong unifying power due to its linking of concepts from biology, psychology and neuroscience (Seto & Lalumiere, 2010). It also draws on a range of sexual offending theories that are currently accepted (Ward & Beech, 2006). Theories of sexual offending are resources that spell out the aims of intervention, the nature of therapeutic practices and instruct practitioners how to work with individuals who have engaged in abusive behaviour. In this way, the ITSO can be used as a comprehensive framework for a case formulation which includes the developmental factors that make individuals vulnerable to committing a sexual offence (Ward & Beech, 2006). In order to apply this theory specifically to sexual offenders with intellectual disabilities, future research needs to identify which aspects of this theory are more salient. It is possibly for this reason that the theory does not define or specify some of its factors, such as exactly which genetic pre-dispositions could be involved in sexual offending by people with intellectually disability, or how sexual problems such as paraphilic sexual interests, excessive sexual drive, or sexual

preoccupation arise from other problems they considered in people with intellectual disabilities (Seto & Lalumiere, 2010).

Self-regulation model (Ward & Hudson 2000)

The self-regulation model of sexual offending (Ward & Hudson, 1998, 2000) is an offence process model which includes the cognitive, behavioural, affective, and contextual factors that lead to the occurrence of a sexual offence. The model was developed as a result of theoretical and practical problems with the traditional relapse prevention approach to sexual offender treatment and from empirical evidence identifying variability in the offence chain among sexual offenders.

The self-regulation model includes nine phases in the offence progression along with four pathways to sexual offending (Ward & Hudson, 1998, 2000). According to the model, offenders engage in goal-directed action and are guided by various internal and external processes. Specifically, offenders may be influenced by desired states and/or circumstances and thus, are motivated by approach goals. In contrast, some offenders desire to avoid such situations and/or circumstances and thus, are guided by inhibitory goals. Furthermore, strategies that are either passive (i.e., non-complex) or active (i.e., complex) in design are implemented in order to achieve the predominant goal selected by the individual.

According to self-regulation theory (Carver & Scheier, 1990), inappropriate strategies are defined as either: (1) under-regulated (i.e., a failure to control behaviour); or, (2) mis-regulated (i.e., inappropriate strategies to achieve desired goals). An individual can also exhibit intact self-regulation,

where the strategies are effective in achieving desired goals but, with sexual offenders specifically, the goals are problematic. The combination of goals and strategies culminate in a predominant offence pathway to sexual offending. The nine phases are outlined briefly below, followed by the four pathways to sexual offending.

Phase One (life event). According to the model, the initial state of abstinence for an offender is disrupted by a specific event or stressor (e.g., an argument with a partner). Subsequently, the offender evaluates the event in such a way that is consistent with existing implicit theories (see Ward & Keenan, 1999), goals, and the specific context in which the event occurred. The antecedent event and subsequent appraisal is followed by various cognitions and emotions associated with sexually aggressive behaviour and may result in the desire for such behaviour which is accompanied by positive or negative emotional states.

Phase Two (desire for deviant sex or activity). After the initial event and evaluation described in phase one, the offender experiences a desire for sexual or non-sexual aggressive behaviour. This process is relatively covert and is accompanied by either positive or negative emotional states. Again, past memories and existing implicit theories can function to activate the desire.

Phase Three (offence related goals established). Once the desire has been experienced, the offender establishes a goal towards sexually aggressive behaviour. It is in this phase, that the motivation for sexual offending becomes evident. Avoidance goals are reflective of the desire to prevent

offending and are most often accompanied by negative emotional states (e.g., fear), whereas approach goals are indicative of a desire to sexually offend and are associated with either positive (e.g., excitement) or negative (e.g., anger) affective states.

Phase Four (strategy selected). Consistent with self-regulation theory, goals are achieved through the utilization of strategies. During this phase, individuals choose a strategy that is likely to result in successfully achieving their established goal. Strategies can be either overt and explicitly implemented and planned, or they can be relatively covert, with little thought placed on utilization.

Phase Five (high risk situation entered). In this phase, individuals come into contact with a potential victim directly resulting from the prior goal followed and strategy implemented. The response to the situation is dependent on the specific pathway followed. That is, individuals with an inhibitory goal are likely to experience negative affect (e.g., anxiety), although some may also experience increasing sexual arousal. Moreover, they are most likely guided by offence scripts and/or automatic responses to situational cues. In contrast, individuals with an approach goal are likely to experience the need for immediate gratification and will be responding to this need impulsively (i.e., approach-automatic pathway) or through the use of explicit planning (i.e., approach-explicit pathway). The appraisal of the event is positive (e.g., excitement), although some offenders may experience negative emotions, such as anger.

Phase Six (lapse). At this point, individuals are engaging in specific pre-offence behaviour (e.g., massaging the victim). While individuals following

the approach pathways continue in attempting to achieve their original goal through the implementation of specific strategies, individuals following the avoidant pathways switch, albeit temporarily, to approach-motivated desires as a result of the strength and immediacy of the potentially gratifying act. Of note, every individual experiences positive emotional states during this phase given the increase in sexual arousal and the potential outlet for their sexual needs, although for some individuals, negative affect may also be present.

Phase Seven (sexual offence). It has been hypothesized that the offender's perception of the victim and the intrusiveness of the sexual assault is dependent on the pathway followed (Ward et al., 1995). Specifically, offenders will either view the offence as: (1) a caring interaction (i.e., a mutual focus); (2) an event that places their own needs before the victims (i.e., a self-focus); or, (3) an act that places the victim's experience as paramount (i.e., a victim focus). According to Ward et al. (1995) the mutual-focus stance is evident in offenders demonstrating a long duration of offence behaviour with little intrusiveness. The self-focus perspective is exhibited by those who offended in a shorter period of time but with greater intrusiveness. Finally, the victim-focus is not adequately distinguished with regard to offence characteristics. It is suggested that individuals following the avoidant pathways would likely be self-focused, thus demonstrating greater intrusiveness and the approach pathways would focus primarily on the victim, thus demonstrating less intrusiveness but longer duration (Ward et al., 2004); however, this has not been examined empirically.

Phase Eight (post-offence evaluation). After the offence, individuals evaluate their behaviour as it relates to their initial goal. Given that offenders with an inhibitory goal failed to achieve their objective, they are likely to experience negative affect and are likely to experience emotions such as shame or guilt. In contrast, approach-motivated offenders have achieved their goal to offend and, as such, will experience increased self-esteem and positive affect.

Phase Nine (attitude toward future offending). This phase explains the process by which offenders evaluate their objectives with respect to future offending. It is suggested that offenders with avoidant goals attempt to re-establish control over their offence cycle and resolve to avoid future sexual aggression. In contrast, approach-motivated offenders experience positive reinforcement of their recent behaviour and further improve self-regulatory strategies to offend sexually. Of note, attitudes toward future offending may markedly differ from the original goals established in the beginning of the offence cycle. As such, the model specifically allows for changes in pathways across time. The process depicted above describes the offence process followed by sexual offenders. The nine-phase model provides the necessary information to establish the predominant offence pathway followed. Each pathway is described below.

The *avoidant-passive* pathway is characterized by a desire to refrain from offending but the individual lacks the necessary coping strategies to achieve this inhibitory goal. These offenders utilize passive or covert strategies (e.g., ignoring the deviant thoughts) to abstain from offending and, as such, are representative of an under-regulation self-regulatory style. The

strategies employed are insufficient to prevent offending, sometimes resulting in a sexual offence. Following the offence, the offender will experience negative affect (e.g., guilt, shame) given the failure to achieve the desired goal.

The *avoidant-active* pathway is characterized by a mis-regulated self-regulatory style. Offenders following this pathway desire to avoid the sexual offence, and active strategies are employed, such as alcohol use, to suppress deviant sexual fantasy. This strategy is counterproductive, in that a sexual offence often results from the strategy employed. Following the offence, the offender will experience negative affect (e.g., guilt, shame) due to self-regulatory failure.

The *approach-automatic* pathway to offending is characterized by an under-regulated self-regulation style and a desire to offend sexually. As such, this pathway to offending is diametrically opposed to the offence progression described in the Relapse Prevention model. Moreover, this pathway is dominated by impulsivity with regards to planning the sexual offence. That is, planning to offend sexually is unsophisticated and rudimentary in manner. Following the offence, the offender likely experiences positive affect (e.g., increased self-esteem), as his goal to sexually offend has been achieved.

Finally, the *approach-explicit* pathway is characterized by intentional and conscious planning of the sexual offence along with explicit strategies to achieve this goal. As such, this pathway represents an intact self-regulation style. The offence process is well-planned and the offender maintains positive mood states throughout the offence process. The offender likely

experiences positive affect (e.g., elation) following the offence, as he has achieved his original goal to offend sexually (Ward & Hudson, 2000; Yates & Kingston, 2005).

The research to date has been supportive, some of which is described next. Webster (2005) interviewed 25 treated sexual recidivists who had offended against either a child or adult and used grounded theory analysis to evaluate the content validity of the self-regulation model. The responses were reliably allocated to the individual phases and the overall pathways identified in the model. Moreover, the predominant pathway demonstrated pre- and post-treatment was approach-explicit and the particular pathway followed was stable; that is, did not change when evaluated pre-treatment and posttreatment. The over-representation of the approach-explicit pathway may have resulted from the focus on sexual recidivists and the results may not be generalizable to samples comprised of non-recidivists.

Yates and Kingston (2006) evaluated the relationship between offence pathways and risk to re-offend sexually. Specifically, 80 treated sexual offenders (both rapists and child molesters) were classified to one of the four pathways based on detailed file review. Results indicated that significant differences were evident among the various types of sexual offenders (e.g., rapists versus intra-familial offenders) and the specific pathway followed. That is, the avoidant-passive pathway was comprised predominately of intra-familial offenders (81.8%), whereas the approach-automatic pathway consisted primarily of rapists (82.6%). The approach-explicit pathway was comprised almost equally of child molesters with male victims (24.4%), intra-familial offenders (29.3%), and rapists (29.3%).

Overall, the rapists and child molesters with male victims tended to follow the approach pathways, whereas the intra-familial offenders were distributed across both approach and avoidant pathways. With regard to risk to re-offend, offenders following the avoidant-passive pathway scored lower on the Static 99 (Hanson & Thornton, 1999) and a dynamic measure of criminality (Wong, Olver, Nicholaichuk, & Gordon, 2000) than the approach-automatic and approach-explicit pathways. Moreover, individuals exhibiting an approach-automatic pathway scored higher on the measure of criminality when compared to the approach-explicit group. While the reliability of the coding methodology was marginal (kappa = .61), the method used was relatively unstructured, in that there was no set criteria for pathway classification. Therefore, it was hypothesized that structured guidelines for pathway assessment would improve on the reliability of coding.

In discussing the theoretical relevance of the self-regulation model to sexual offenders with intellectual disabilities, Keeling & Rose (2005) proposed that these offenders may be more likely to offend via the approach-automatic or avoidant-passive pathways. Some studies have examined the hypotheses of Keeling & Rose (2005). Courtney et al. (2006) have examined the experiences of sexual offenders with an intellectual disability using a qualitative, grounded theory approach in order to develop a tentative model of the offence process. They found that participants tended to blame others, claimed ignorance of social skills, denied their status as offenders and perceived themselves as victims. These characteristics share similarities with the approach-automatic pathway and Courtney et al. (2006) suggest the need for further empirical examination investigation to

examine whether sexual offenders with intellectual disabilities follow this pathway more often than the other three pathways. Langdon et al. (2007) have examined the offence processes of sexual offenders with intellectual disabilities. They found that the largest group was in the approach explicit pathway, followed by the approach-automatic pathway. However, the smallest group was in the avoidant- passive pathway. In examining the self-regulation theory with sexual offenders with special educational needs compared with mainstream sexual offenders, Keeling et al. (2006) found no significant differences between representations in pathways between these two groups. In this case the largest number of offenders was in the approach-automatic followed by the approach-explicit group. Therefore, the self-regulation model (Ward & Hudson 2000) appears to have utility in examining the offence processes of sexual offenders with intellectual disabilities, but whether members of this group are more likely to offend via the pathways associated with poor self-regulation remains a question for further research.

Despite the fact that the self-regulation model represents an improved theoretical construct when compared to the earlier Relapse Prevention model and that some preliminary empirical support has now been ascertained, as described above, there are some potential limitations. Specifically, some investigators have questioned the extent to which possible alternative offence processes and/or pathways (e.g., individuals who display multiple pathways) are evident, beyond those described in the model (e.g. Ward et al., 2006). Moreover, Marshall and colleagues (Marshall, et al., 1999; Marshall, Marshall, Serran, & Fernandez, 2006) have questioned the extent to which the development sample, which was

comprised of untreated sexual offenders, may have compromised the formation of the nine phases. In other words, given that untreated sexual offenders may be less aware of important distal factors implicated in their offence process, the identification of important factors based on the report of untreated individuals may not be entirely accurate.

Theories of sexual offending in people with intellectual disabilities

Craig and Lindsay (2010) identify theories of sexual offending by men with intellectual disabilities and argue that such behaviour is unlikely to be comprehensively described by a single theory but by a combination of several theories including tendencies towards sexual offending, personality traits and impulsiveness, alongside the hypothesis of counterfeit deviance. This section considers some of the main hypotheses for explaining sexual offending in people with intellectual disabilities.

Counterfeit Deviance was first described by Hingsburger, Griffiths and Quinsey (1991) and attempts to explain that inappropriate sexual behaviour in men with intellectual disabilities has been precipitated by factors such as poor social and interpersonal skills, lack of sexual knowledge, limited opportunities to establish appropriate sexual relationships and sexual naivety rather than deviant sexual interests (Lindsay & Taylor, 2010). Luiselli (2000) referred to this theory as the most influential basis for the development of treatment services for intellectually disabled sex offenders. However, a number of studies have questioned its validity, specifically in the area of sexual knowledge. In an evaluative study of the Assessment of Sexual Knowledge (ASK) tool (Butler, Leighton & Galea, 2003) it was found that intellectually disabled offenders actually had good sexual knowledge,

especially in relation to parts of the body and public versus private places (in terms of engaging in sexual activity) (Galea, Butler, Iacono and Leighton, 2004). In another sexual knowledge assessment study, Lunksy, Frijters, Griffiths, Watson and Williston (2007) compared a cohort of men who had committed sexual offences, with controls who had committed no sexual offences. They split intellectually disabled sex offenders into those who had committed repeated forced offences, and those who had committed inappropriate sexual behaviours (such as masturbation or touching), and they found that repeated and forceful offenders had higher sexual knowledge than non-offenders. However, the inappropriate offenders had a level of knowledge and attitudes similar to non-offenders. This suggests that the counterfeit deviance hypothesis may still apply to the inappropriate offenders group, rather than persistent deviant offenders. Conversely, Rice, Harris, Lang and Chaplin (2008) found that intellectually disabled sex offenders, like sex offenders in general, commit sexually abusive behaviour largely based on deviant sexual interests, not because of sexual ignorance or poor social skills. Taking these various studies into account, Lindsay (2009) constructed a revision of the Counterfeit Deviance hypothesis. He postulated that although sex offenders with intellectual disabilities may have a higher level of sexual knowledge and more liberal sexual attitudes than non-offenders, their sexual knowledge remains at a stage where it is considerably lower than non-intellectually disabled men. In addition, although they may also understand something of the illegality of inappropriate sexual behaviour, they may not have a full comprehension of the extent to which such practices are condemned by society. This

relative lack of understanding may interact with the need for sexual contact, resulting in sexual offending behaviour (Craig & Lindsay, 2010).

Tendencies towards Sexual Offending is the hypothesis that persistent sexual offending is as a result of deviant sexual interests mediated by cognitive distortions and attention to selective cues that are interpreted in a sexual manner (Craig & Lindsay, 2010). As shown by Rice et al. (2008) intellectually disabled sex offenders have shown the same primary motivations of sexual preference and drive shown by mainstream sex offender studies. Lindsay and Taylor (2010) suggest that looking at offending patterns provides further evidence of this. Day (1994) reported that all 31 of his intellectually disabled sample had previous recorded incidents of inappropriate sexual behaviour, and Lindsay et al. (2002) found previous convictions or reports of offending in 62 % of the referrals to a treatment service. What has been argued is that given the disincentives for continued offending, sexual preference must be a significant factor (Lindsay & Taylor, 2010). Blanchard et al. (1999) in their study of 950 sex offenders, reported that 'lower functioning' sexual offenders were significantly more likely to commit offences against younger children and male children. In a further (meta-analytic) study by Cantor, Blanchard, Robichaud and Christensen (2005) which reviewed the IQ and sexual offending data of 25,146 sex offenders and controls, a relationship between lower IQ and paedophilia was found, supporting the notion that both intellectually disabled and general offenders are motivated by specific sexual preferences. Therefore, sexual drive and sexual preferences may be important considerations within a treatment programme (Craig & Lindsay, 2010).

Sexual Abuse is the hypothesis that there may be an association between sexual abuse in childhood and sexual offending. Hayes (2002) suggests that this is one of the many similarities between intellectually disabled sex offenders, intellectually disabled non-sex offenders and non-disabled sex offenders. Lindsay, Law, Quinn, Smart and Smith (2001) compared the physical and sexual abuse histories of 46 sexual and 48 non-sexual offenders with intellectual disabilities and found that 38 % of the sexual offenders and 12.7 % of the non-sexual offenders had experienced sexual abuse while 13 % of the sexual offenders and 33 % of the non-sexual offenders had experienced physical abuse. This study gave some support to the hypothesis that experience of sexual abuse in childhood will promote a cycle in which the individual 'acts out' their childhood experiences with others in the form of sexual abuse (Craig & Lindsay, 2010). Other studies have also found high rates of physical and sexual abuse among intellectually disabled sex offenders (Hayes, 2004; Sex Offender Treatment Services Collaborative: Intellectual Disability [SOTSEC-ID], 2010). Lindsay et al. (2001) conclude that sexual abuse in childhood may be a significant variable in the development of sexual offending in later life. Hayes (2010) concludes that intellectually disabled sex offenders are more likely than non-offenders to have attachment disruption, to have experienced abuse, to be aggressive, to have deficits in executive functioning, and suffer from a number of mental, behavioural and emotional difficulties due to these early experiences.

Personality Characteristics and Impulsivity Some authors have hypothesised that impulsivity is likely to be a feature relating to

intellectually disabled sex offenders (Caparulo, 1991; Hayes, 1991). Glaser and Deane (1999) studied 120 offenders with intellectual disability and concluded that for some offenders, sexually abusive behaviour is part of a pattern of impulsivity rather than explicit sexual deviation or preference. Conversely, Parry and Lindsay (2003) compared 22 sex offenders, with groups of non-sexual offenders and non-offenders, all with intellectual disability, using the Barratt Impulsiveness Scale (BIS) and found that sex offenders reported significantly lower levels of impulsivity in all areas than their comparison groups. These authors noted that the high frequency of grooming behaviour by such offenders, suggested that they were aware of the importance of gaining the victims' trust and friendship and also suggested an ability to delay gratification to some extent, which is exactly the opposite to the features of impulsiveness. However, it may also be the case that different categories of sexual offender could show differences in impulsivity, e.g. offenders against children may have a greater ability to plan and delay gratification than offenders against adults, who may have a greater tendency to act on the spur of the moment.

Ethical Considerations

The following case study is based upon a factual account of the assessment of an 18 year old adolescent male admitted under the Mental Health Act (1983) to a psychiatric secure hospital for persons with learning disability. The client's Responsible Clinician (Forensic Psychiatrist) deemed the client to have capacity to consent and the client, along with three of his family members, all gave their informed consent that the Trainee Forensic Psychologist may use information gathered in the writing of this case study. To maintain anonymity, the client's name has been changed.

Part 1: *Case Presentation*

Jack, an 18 year old male, was sentenced to a 5 year hospital order in 2012 after he was found unfit to plead to the charge of rape. The offence took place two years previous when Jack was 16 years of age and the victim, his second cousin, was 12 years old. Following Jack's arrest, he was bailed and supervised by his uncle until the case came to court. Upon conviction he was admitted to a sex offender assessment and treatment unit for adult males with a learning disability.

Definitional Considerations and Organisation Details

To be admitted to the hospital where Jack resided patients will be:

- Known or suspected to have a severe mental handicap as defined in the Mental Health (NI) Order 1986
- Be over 18 years of age and subject to part 2 (civil detention) or part 3 (hospital order) of the Mental Health (NI) Order 1986
- Be currently, or have been subject to the judicial process, but on occasion consideration will be given to the admission of individuals with non-adjudicated offending histories

The Mental Health (N. Ireland) Order 1986 defines Mental Disorder as: *Mental illness, mental handicap and any other disorder or disability of mind.*

The following terms, further defined in the Act, are relevant to people with learning disabilities:

- **Mental Handicap:** *a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning.*

- **Severe Mental Handicap:** *a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning.*
- **Severe Mental Impairment:** *a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.*

Of note, these definitions omit a key feature included in all international definitions used so that people can be reliably and validly classed as 'learning disabled', namely that the disability or impairment is present from childhood. Furthermore, the term 'development of mind' is impossible to define accurately (Foundation of People with Learning Disabilities, 2001).

Within this Order, it should be observed that the definition of *severe mental impairment* is identical to that of *severe mental handicap*, save for an additional 'conduct' criterion.

Since a Treatment (hospital) Order in Northern Ireland can be invoked only in a case of *severe mental impairment* (with its attendant severe impairments of both intelligence and social functioning), this makes it crucial for accurate operational distinctions between *significant* and *severe* impairments to be agreed in that particular context. In Northern Ireland, if an individual has a mild learning disability but *not* a severe mental impairment then they cannot be detained under Mental Health Legislation.

The British Psychological Society (2001) stress that for a person to have a learning disability, there are three core criteria which must be met:

- Impairment of intellectual functioning (IQ 69 or below)
- An impairment of social and adaptive functioning
- Age of onset before adulthood (under 18 years of age)

The client Jack was assessed as being in the mild range of intellectual impairment (see results of WISC on page 206). At the time of undertaking this assessment piece (January-September 2012) I was not aware if/that Jack was screened to assess for an impairment of social and adaptive functioning. This method of assessment is generally a screening tool used to determine the presence of any difficulties with practical everyday skills required to function and meet environmental demands, including those needed to effectively and independently care for one self and to interact with others. In relation to age of onset before 18 years, records indicate that Jack did not attend a school for children with special educational needs. To the extent that the client fulfils the criteria for a learning disability, I am certain that Jack meets one of the three criteria, since I had access to a report by a clinical psychologist who applied the WISC and found the client to have an IQ between 50-69 (see page 206). Jack was described as having a learning disability, and his level of intellectual functioning is commensurate with that. I presumed that Jack must also be regarded as having a significant impairment in social functioning for the fact that he was admitted to the unit under the Mental Health (NI) Order 1986.

Assessment Interview

A semi-structured interview was completed, including family, forensic and educational histories.

Personal History

Jack described that he lived with his mother, father and siblings until the index offence aged 16 years. Following his arrest, he resided with his uncle until admission to the forensic unit.

Jack knew little about his birth or how he was as a baby and toddler. When asked about his mother, Jack told the psychologist she was unemployed, and that prior to the index offence, he would have gone shopping with his mum, also they spent time together watching soaps. Since admission to hospital Jack's mother has maintained a high level of contact with him via telephone and in person through visits.

Jack was unable to discuss his father in much detail during the assessment, apart from stating he was in full time employment and that they spoke less frequently compared to the amount of contact Jack had with his mother. Jack remarked that if his father was not at work he would be at home, watching football on the television and he knew to leave him alone.

Jack described that his relationship with his parents was 'getting there'; reflecting that at home his father and mother did not talk to him as much as they have done since his admission to hospital. Jack stated that he did not have any hopes for his relationship with his family. Furthermore, Jack doubted his family had been impacted by the commission of the index offence. It was apparent that Jack was especially close to his uncle. He

offered that his uncle ‘understands me better’ and he can talk to him ‘about anything and everything’.

Relationships

Jack advised that he has had one romantic relationship in the past. He was at college at the time and his girlfriend was a younger pupil there. The relationship was not of an intimate kind; rather it consisted of passing ‘love letters’ to each other in the classroom. Jack said that he did not see his girlfriend outside of school and within a few weeks the relationship came to an end when he learned that one of his friends initiated getting together with her. Jack recalled that he felt like ‘punching the head off him’, however he did not retaliate. Jack was on study leave at this stage and reports that his thoughts and behaviour turned towards ‘getting on with life’.

Jack states that he has never been in love before and views a sexual relationship as something he would seek when he feels ready to start a family. According to Jack, the appropriate age to begin having a family is when a person is in their mid 20’s.

Education and career goals

Jack reported that he disliked having to do homework such as English and Maths; however, opportunities to participate in manual activities such as bricklaying and basic vehicle maintenance appealed to him greatly. Jack reported that he has been awarded certificates in these vocational subjects. He informed that he would like to have his own business once he is discharged from hospital. Jack spoke of his keenness to combine his knowledge of auto mechanics and interest in gardening to offer a digger and excavation service in the future. When asked what problems he might

have in achieving this goal, Jack stated that he had not given it any prior consideration.

Substance Misuse

Jack asserted that he would drink alcohol on special occasions, for example, on his birthday or at holiday times such as Christmas. He does not report to have a strong desire to drink alcohol; offering that at most he would have drank 2-3 Alco pops in one evening. This makes him feel 'happy'. Jack told the psychologist that he had not experimented with any kind of illegal drug or substances and was resolute in his opinion that drugs 'get you into trouble' and result in 'bigger sentences', something that he wishes to avoid.

Emotional Control

Jack stated that he gets angry at his elder brothers when they make derogatory comments about his physical appearance. He has responded by being aggressive towards them and/or taking his aggression out on inanimate objects. According to Jack, his uncle exerts a calming influence on him and is able to help him cool down in a very short space of time (5 minutes). Jack demonstrated insight into self- regulation techniques, stating that in the past he has used counting to ten and thinking about places he has visited before or places he would like to go to, as a means to reduce anger arousal.

Offending history and the index offence process

There is no evidence that Jack has previously been involved in any criminal activity other than the index offence.

As stated earlier, the Four Factor Model by Finkelhor (1984) was originally developed to support the exploration and understanding of factors that lead to adult males sexually offending against children. However, according to Hoghughi (1997), if the model is appropriately adapted it may help to make sense of other forms of abuse and different types of offenders, including adolescents. A simplified version of Finkelhor's (1984) Precondition Model was used with Jack as a framework for organising his offence description. I drew on material within the handbook: *Guide for Comprehensive Assessment and Individual Work with a Young Person who has Sexually Harmed* (G-Map, 2008), and also on the work of Stuart Mulholland, Director of the Welltree Foundation and Child Care Consultant, who provides therapeutic input to a harmful sexual behaviour unit for adolescent males in Scotland, where I had worked previously (2008-2009). This individual had demonstrated to staff that conceptually the model was appropriate to, and could be understood by, teen males with and without intellectual impairment. Therefore, I felt it would be valid to use in this case study. The adapted version of Finkelhor's (1984) Precondition Model was termed the 'Four Steps Model'. The model's four stages, namely motivation to sexually abuse, overcoming internal inhibitors, overcoming external inhibitors, and overcoming the resistance of the victim were adapted to become: 1) Wanting to, 2) Making it OK, 3) Getting the chance, and 4) Making the person go along. The key aims in using this model were to 1) promote an understanding that sexual offending does not 'just happen', and 2) raise awareness that there are several points in between 'wanting to' and 'making the person go along', at which it is possible to stop, employ self-management strategies, and 'turn back'.

It is important to note that this model was initially explored with less threatening and intrusive examples than sexual abuse, e.g. driving too fast and stealing. The understanding gained was considered to then make applying the model to the index offence easier for the young person.

Exploration of Jack's own four steps in the index offence initially proved challenging. He agreed that he must have committed the offence but claimed not to remember any detail. The following statements indicate denial of the first step: 'It was an accident' and 'It just happened'. Regarding the remaining steps, Jack continued to assert that he does not often think about the offence and when it comes to mind, he actively distracts himself from reflecting on the circumstances stating that it is in the past and he wishes to, 'move on'. Jack reported that he desired to remember what he did 'next'; however, at this particular time in the assessment he could not offer a narrative which did not raise more questions than answers.

File information highlighted that Jack's mother, father and uncle strongly believe that he is innocent of the offence and that the judicial system has treated him unfairly. At the time of assessment Jack's uncle was considering lodging an appeal against the conviction.

Psychometric Tests

A battery of self-report adapted psychometric tests were administered in order to help aid in the identification of relevant risk and needs. Questions within the psychometric tests were presented verbally due to the reading difficulties of the client, an appropriate method of assessment identified for this population (Boer et al., 1995).

Family Relations

The Bene-Anthony Family Relations test examines the young person's perception of the dynamics within their family. Having chosen 3D figurines to represent the members of the young person's family, the individual "posts" messages as s/he deems appropriate to the different family members. Messages that the young person feels do not apply to anybody in the family are given to the `Mr. Nobody' figure.

The *valence* of each card is either positive ('this person in the family is kind to me') or negative ('this person in the family is never satisfied').

The *strength* of those examples is mild: there are also strong positive messages ('this person in the family cares more for me than for anybody else') and strong negative messages ('sometimes I hate this person in the family').

Direction is either outgoing (feelings coming from the child, e.g. 'I like to hug this person in the family') or incoming (feelings going towards the child, e.g. 'this person in the family is mean to me').

Jack thus had eight different kinds of messages before him (two by two by two), plus a series of maternal overprotection statements ('Mother worries that this person in the family might get hurt') and parental overindulgence cards ('this is the person in the family father/mother spoils too much').

Table 8. Client's distribution of feelings

	Jack → Others		Others → Jack		
	Outgoing Positive	Outgoing Negative	Incoming Positive	Incoming Negative	Degree of Involvement
Father	0	0	1	1	2
Mother	2	1	1	4	8
Brother 1	1	0	0	2	3
Brother 2	0	0	1	0	1
Sister 1	1	1	2	0	4
Sister 2	2	2	0	0	4
Sister 3	0	3	0	0	3
Sister 4	3	0	1	1	5
Sister 5	1	0	0	0	1
Sister 6	3	2	2	3	10
Uncle	2	5	3	1	11
Self	2	0	5	0	7

The total number of items assigned to each family member indicates the measure of emotional involvement with that person. Jack's pattern suggests that he overlooks almost everyone except for his uncle and youngest sister. The uncle usually a peripheral family member, was awarded the greatest allocation of cards: eleven. It is worth noting that there was an exaggerated response to Jack's father who obtained a score of two. It could be argued that the test results show a marked displacement of feelings of a very loving character on to the uncle rather than the father who would normally be considered a 'central' family member.

The highest number of incoming positive feelings came from Jack himself. On the basis of clinical experience, one could expect a high self-love response in privileged or over-indulged children.

Jack acknowledged the greatest measure of hostility experienced as coming from his mother (four items).

In Jack's responses the person who received the most outgoing negative feelings items (five) was his uncle. Given that Jack reported to have a close relationship with his uncle and there has been no external evidence of concern regarding their interactions when his uncle visits Jack, it is interesting that the results reveal a different picture (a failure to deny presence of strong negative feelings) in the test situation. Jack differentiates his feeling experiences with his siblings and results suggest that he has the strongest outgoing positive feelings for sister no. 4 and sister no. 6. A full description of the Family Relations Test and psychometric properties can be found in Chapter 4. It has been shown that the Family Relations Test is applicable for adolescents with a learning disability, please see Appendix 21 for further information.

Self-esteem

Self-esteem is a term that reflects a person's overall appraisal of his own worth. According to Marshall, Barbaree, and Fernandez (1995), there is evidence to support the idea that sexual offenders are lacking in self-confidence. With the lower functioning group, the research in this area has focused on the repeated experience of failure which tends to contribute to low self-esteem in this client group (Coleman & Haaven, 2001). Jack answered 'yes' to all eight items on the Adapted Self-esteem questionnaire,

indicating that he recognizes strengths about self and holds a positive picture of himself. This result can be viewed as a desirable one in light of the fact that researchers Marshall, Champagne, Sturgeon and Bryce (1997) reported that enhanced self-esteem facilitated the attainment of other treatment goals, and Marshall (1997) found raised self-esteem to be associated with reductions in deviant arousal. Jack's score is much higher than the average untreated ID sexual offender given the mean for this population pre-treatment is 4.10. Following intervention, it would be hoped that this result does not drop significantly, rather it remains the same. A description of the Adapted Self-esteem Questionnaire, and the psychometric properties of this scale can be found in Appendix 17.

Lifestyle impulsivity

Impulsivity reflects a tendency to act without thinking about long-term consequences. Lifestyle impulsiveness is reported as a common feature amongst learning disabled sex offenders. They are less able to project their life into the future and understand the consequences of their actions (Knopp, 1990). Cullen (1993) observes that the offence characteristics of learning disabled offenders suggest poor impulse control. The offences are characterized by offenders moving from situations which trigger arousal into committing the abuse in short spaces of time. Prentky (1992) states 'Lifestyle impulsivity has been found to be a powerful predictor of rape'. The fact that this dimension has emerged as an important discriminator across such widely divergent samples suggests that it is a powerful theoretical component of rape' (pg.7) Out of a possible score of 26 on the Adapted Impulsivity scale, Jack obtained 12. This highlights that Jack describes

himself as exhibiting a degree of impulsivity. Jack endorsed items including making up his mind quickly, getting carried away with ideas and often getting involved in things he later wished he had not involved himself in. To this end, Jack would benefit from further work in this area to help him recognize with greater accuracy his tendency to rush into things without thinking about them, to develop and practice strategies for thinking about the consequences of actions and to set realistic personal life goals and practice strategies for achieving them. The pre-treatment mean of ID sexual offenders is 13.27; therefore, Jack's score is on a par with this. Ideally post treatment it would be desirable for this figure to go down. A description of the Adapted Impulsivity Questionnaire, and the psychometric properties of this scale can be found in Appendix 18.

Anger/Hostility

Grievance thinking is a dynamic risk factor that can be targeted in treatment, and is characterized by a perception of being wronged accompanied by angry, hostile rumination about revenge, and has similarities to the "dangerous world" implicit theory. Rumination is an important part of "grievance thinking ", which has been linked to recidivism in sexual offenders. A popular measure for this risk factor is the Adapted Ruminations Scale. Rumination refers to thoughts that are conscious, recurring, and not demanded by the individual's current environment. Ruminative thoughts occur repetitively and are difficult to eliminate. Jack obtained a score of 8 out of a possible 30. Whilst this sum does not suggest that he is inclined to ruminate angrily and bear grudges it is important to balance this with remarks made about his victim, disclosed during the clinical interview. It is suggested that treatment should incorporate teaching

to enable Jack to develop skills to change and manage these hostile feelings and thoughts and practice these in difficult situations. The pre-treatment mean in ID sexual offenders is 7.96, comparing this with Jack's score suggests that this may be a problematic area for him. Following intervention, it would be expected that Jack shows a clinical improvement, i.e. reduction, on this domain. A description of the Adapted Ruminations Questionnaire, and the psychometric properties of this scale can be found in Appendix 19.

Sexual Attitudes and Knowledge Assessment

This protocol is designed to assess knowledge of sexual matters, sexual anatomy and relationships across four domains: sexual awareness, assertiveness, understanding relationships and social interaction. Individuals are asked to respond to a series of questions, each accompanied by a picture.

Jack has a general understanding of male and female children and adults. He also has an awareness of his own body parts- Head, Arms, Legs, Stomach, Feet, Hands, Fingers, Lips, Eyes, Nose, Hips etc. Jack was able to identify how males and females change when they become teenagers and later reach adulthood. That said, Jack's answers involved the obvious physical differences between boys and men and girls and women such as: breast growth, hair on legs and pubic area. He did not consider things like voice changes or development of muscle.

Jack reported exposure to pornography and informs he became aware of many aspects of sexuality through watching television. Jack used slang

names when talking about female body parts and did not appear to know correct names for some sex organs.

Jack has a true understanding of menstruation in certain respects and a muddled understanding in others. For example, he knows the age at which a female usually has a period and what this means, yet incorrectly reported the frequency of a menstrual cycle and when menstruation stops occurring.

Jack appeared to have insight into unsafe/inappropriate touching of his own private parts and that of others claiming that inappropriate touches are wrong and against the law. If he found himself in a situation where someone else's behaviour towards them was unacceptable he stated that he would run away from this and telephone the Police.

Despite acknowledging that anyone who is touching another person on the breasts, penis, or pelvic area, or who tries to kiss another person without that person's consent is performing a so called 'bad' touch, Jack did not connect this with the fact that the victim of his index offence did not want to have sex with him.

Jack was very clear about the need for sexual behaviour to take place in private, commenting that if it were to happen in public others may record the sexual behaviour and upload it onto YouTube resulting in feelings of embarrassment for the persons involved. He expressed a desire to have a sexual relationship with a female when he reaches his twenties and added that at that stage in his adult life he anticipates he would like to start a family with his partner. Self-report indicates that Jack explains sex happens primarily for making babies. Jack acknowledged using masturbation as a way to express his sexual feelings.

An overview of the Sexual Attitudes and Knowledge Scale can be found in Appendix 20.

Offence Related Attitudes

Jack completed the Questionnaire on Attitudes Consistent with Sexual Offending (QACSO) as a means of exploring his attitudes and beliefs about issues that have been found to have relevance to sexual offending. The QACSO has been designed specifically for use with populations who have an intellectual disability. For a description of this measure and the psychometric properties of this scale please see Appendix 21.

There are 7 subscales of the QACSO:

- Rape and attitudes to women
- Voyeurism
- Exhibitionism
- Stalking
- Dating abuse
- Homosexual assault
- Offences against children

Normative information is available to allow comparisons with 4 groups – people who sexually offend with intellectual disability (I.D.), people who offend (non-sexual) with intellectual disability, non-offenders with intellectual disability, and mainstream males (non-offenders).

Rape and Attitudes to Women Jack's score was consistent with non-offenders with I.D. and significantly lower (better) than the score of those with I.D. who sexually offend.

Voyeurism Jack scored above average on this subscale compared with other sex offenders with I.D and significantly more so in relation to the three other participant groups. This indicates the need for further attention to be given to the range of statements he endorsed.

Exhibitionism Jack's score on this scale was consistent with other people who have I.D and sexually offend. The value was greater than mean scores for offenders with I.D, non-offenders with I.D and mainstream males.

Stalking and Sexual Harassment Jack's responses to the items listed here indicate that he holds similar attitudes to the mainstream male population (non-offenders).

Dating Abuse Jack's score was comparable to non-offenders with I.D and approximately half of the mean score obtained amongst sex offenders with I.D.

Homosexual Assault Jack's responses to the items listed here indicate that he holds similar attitudes to the mainstream male population (people who have not been charged with sexual offences).

Offences Against Children Jack scored above average when compared with the scores of offenders with I.D, non-offenders with I.D and mainstream males. However, it was less than the value typically obtained by sex offenders with I.D.

Wechsler Intelligence Scale for Children (WISC)

Whereas the former assessments were applied by the trainee as part of this assessment, the information set out below has been taken from a report by a clinical psychologist who was asked to assess Jack's IQ in order to inform a decision about his capacity to be interviewed in relation to the index offence. Administration of The Wechsler Intelligence Scale for Children-IV indicates that Jack's full scale IQ which is derived from the combination of the four indexes: Verbal Comprehension; Perceptual Reasoning; Working Memory and Processing Speed, places him in the mild range of intellectual impairment (IQ 50-69; WHO (1992) ICD-10th Revision). Approximately 0.2 percent of his age-matched peers would have been expected to obtain a similar or lower score.

Verbal Comprehension Index is a measure of verbal concept formation. It assesses children's ability to listen to a question, draw upon learned information from both formal and informal education, reason through an answer, and express their thoughts aloud. It can tap preferences for verbal information, a difficulty with novel and unexpected situations, or a desire for more time to process information rather than decide "on the spot." It is a good predictor of readiness for school and achievement orientation, but can be influenced by background, education, and cultural opportunities. Jack's scores were consistent within this domain, falling in the 'mild range' of cognitive impairment, approximately 0.5% of his age-matched peer group would have been expected to obtain a similar or lower score.

Perceptual Reasoning Index is a measure of non-verbal and fluid reasoning. It assesses children's ability to examine a problem, draw upon

visual-motor and visual-spatial skills, organize their thoughts, create solutions, and then test them. It can also tap preferences for visual information, comfort with novel and unexpected situations, or a preference to learn by doing. Jack's score fell within the 'mild range' of cognitive impairment; approximately 1% of his age-matched peer group would have been expected to obtain a similar or lower score.

Working Memory Index is a measure of working memory. It assesses children's ability to memorize new information, hold it in short-term memory, concentrate, and manipulate that information to produce some result or reasoning processes. It is important in higher-order thinking, learning, and achievement. It can tap concentration, planning ability, cognitive flexibility, and sequencing skill, but is sensitive to anxiety too. It is an important component of learning and achievement, and ability to self-monitor. At the time of assessment Jack's ability fell within the 0.3 percentile whereby 0.3% of his age-matched peers would have been expected to obtain a similar of lower score.

Processing Speed Index is a measure of processing speed. It assesses children's abilities to focus attention and quickly scan, discriminate between, and sequentially order visual information. It requires persistence and planning ability, but is sensitive to motivation, difficulty working under a time pressure, and motor coordination too. Cultural factors seem to have little impact on it. It is related to reading performance and development too. It is related to Working Memory in that increased processing speed can decrease the load placed on working memory, while decreased processing speed can impair the effectiveness of working memory. Jack's processing speed was his strongest domain, suggesting that Jack may

understand and use visual information more readily than auditory information. Despite this only 4 % of age matched peers would have been expected to obtain a similar or lower score.

Clinical evaluation of language fundamentals (CELF)

CELF-IV (UK) (Semel, Wiig, and Secord, 2003) is an individually administered clinical tool for the identification, diagnosis, and follow-up evaluation of language skill deficits in school-age children, adolescents, and young adults. It was designed to identify individuals aged from 6 years to 21 years who lack the basic foundations of content and form that characterise mature language use: word meanings (semantics), word and sentence structure (morphology and syntax), as well as the recall and retrieval of spoken language (memory). The CELF-IV is scored against a normative sample and thus Jack's performance is compared against his non-learning disabled group.

The ***Core Language*** domain is a measure of general language ability. Jack's performance in this domain indicates that approximately 0.1 % of his age matched peers would be expected to perform similarly or lower.

The ***Receptive Language*** Index is a measure of listening and understanding what has been said. This represented a relative strength for Jack in comparison to skills in other language domains, however, only 5% of his age matched peers would be expected to perform similarly or lower.

The ***Expressive Language*** Index is an overall measure of expressive language skills. Jack's performance in this domain indicates that less than

0.1 % of his age matched peers would be expected to perform as low or lower than him.

Jack's performance in language across all subtests yielded age equivalence ranging from 4 years 6 months to < 9 years. Given his chronological age the discrepancy highlights his deficits in language.

Psychological Formulation of offending and problematic behaviours

The assessment findings were used to formulate a number of clinical hypotheses about the client's problem behaviour and to derive a related treatment strategy. The enmeshed nature of Jack's familial relationships growing up and the crowded living arrangements are thought to be an important factor in the lack of development of self-regulation behaviours.

It is perceived that Jack's elder brother's emotional dysregulation shown towards him probably acted as antisocial modelling for Jack during his development, leading to a lack of emotional regulation skills. Archival reports suggest that following arrest for the index offence Jack's mother attended his GP advising that he was behaving aggressively and non-compliant towards his parents and brothers.

There is a query over whether Jack suffered abuse in childhood. Reports from local social work teams compiled prior to Jack's admission to hospital highlight ongoing difficulties they encountered in relation to assessing and monitoring the home situation and impact on each individual within the family. This was reportedly due to non-compliance, secretiveness, denial and occasional verbal aggression towards social workers on visits. In the period since Jack's arrest until his conviction and subsequent hospital

admission to the forensic unit, Jack was bailed by his uncle who provided a caring role for him whilst in his grandparent's home. Sources reveal that he slept in his uncle's bed despite there being one for him to sleep in on his own. The difficult interactions documented by social services prompted me to consider why they presented in this manner- is it to keep professionals from discovering a past history of sexual abuse by caregivers? Also, given the fact that Jack's uncle from the very outset has taken on such a prominent role regarding his nephew's management, the striking physical resemblance which they share, coupled with the reports of them sleeping together in the same bed, I am puzzled by the exact nature of the relationship Jack's uncle has with him. However, when asked directly Jack denied any experiences that he considered to be physically or sexually abusive during his childhood or adolescence.

Regarding precipitating/antecedent factors, witness statements by the victim acknowledge that a few weeks prior to the index offence, Jack had tried to engage the girl in behaviour against her will. The victim reported she had been at home sitting on the kitchen counter top with her head bent over knees because she was feeling poorly. Jack approached her and lifted her head up in an effort to kiss her on the lips. According to the victim she pushed Jack away and told his sister who advised her to keep her distance from him in future. In the Ward and Hudson self-regulation model this constitutes an approach goal of intimate interaction with the victim. This also represents grooming in the context of sex offender pathways. By going to the victim's house along with his sister Jack engineered the opportunity for physical proximity to her.

A further factor which may also be brought into focus as a precipitant involves the assertion by Jack that on the afternoon of the index offence his mother had warned him 'Just watch [victim] because she slept with her dad'. Jack believed this to be true and this may have lowered his perception of threat from the criminal justice system. Lindsay (2009) has noted that men with intellectual disabilities may have a poorer understanding of the extent to which inappropriate sexuality is condemned by society and this in itself may contribute toward a lowering of the threat threshold.

Without cognitions supporting or justifying the offence it is unlikely that the incident would occur. Psychology sessions with Jack indicated presence of victim blaming. Jack has repeatedly stated that the victim had been trying to attach herself on to him since becoming friendly with his sister in school after they discovered that were second cousins. In the witness statement, the victim asserted that Jack had been the one to move closer to her on the bed that night and regards positioning of them both, states Jack was actually left of her on his brother's bed, not on her right side and as he edged closer, she moved further towards the radiator at the end of the bed. This is noteworthy in the sense that if the victim was there and not Jack, it would be harder for her to flee the situation as she would first have had to get past Jack.

That it was common, according to Jack, for him to view television music channels means that on a regular basis Jack was exposed to sexual material in settings of daily life, and given that some music videos portray sex and violence this potentially may have played a part in creating a context for the sexual behaviour which took place. In addition, the victim claims that Jack kept telling his sister to go to sleep whilst the music was playing on

the television and this rang alarm bells for her because she wondered if Jack was going to try to get further this time with his sexual advances.

Jack remarked that although he does not remember what happened, he harbours ill-feeling about money he has heard the victim will receive in compensation for his actions. It appeared that Jack viewed himself as coming off worse in this situation. It was my impression that Jack may have been too ashamed to admit responsibility for the offence. Because he had denied remembering the offence to his family and the criminal justice system, Jack was now caught in a situation where to admit guilt would result in further difficulty in him being able to effectively deal with negative emotions.

The Integrated Theory of Sex Offending has also been used to generate a formulation.

Pre-disposing factors (Biological Factors)

Learning Disability

Precipitating factors (distal factors, ecological niche)

Rejection by girlfriend

Lack of appropriate intimacy and sexual experiences with others

Internal factors (proximal factors, psychological system)

Impulsivity

Difficulty making and maintaining relationships with others

Little empathy or remorse for his behaviour

Concrete thinking

Increase in hormones in adolescence

Difficulty with identifying and regulating emotions

Attitudes supportive of sexual offending

Presenting problems

Sexual offending

Impulsive behaviour

Poor social skills

Perpetuating factors

Impulsivity

Difficulty with regulating his emotions

Maladaptive coping behaviours

Limited social support network

Family appear to support stance of denial

Protective factors

Increased contact with family

Staff support

Engagement in activities on the ward, and with psychological assessment

Development of hobbies

Intervention

The following describes the application of the Memory Recovery Technique (Marshall, Serran, Marshall & Fernandez, 2005). The aim was to assist Jack to recover memory for the offence as failure to recall offence details prevents offenders from making an appropriate disclosure, which in turn, blocks attempts to identify offence pathways and develop relapse prevention plans. The memory recovery technique is based on experimental literature on memory and was used with 22 clients, 20 of whom showed satisfactory recovery of their memories. This strategy is unlikely to work except in the context of a supportive, empathic relationship with the therapist and therefore in every session (of which there were 26 in total during this placement) I purposely made efforts to build a therapeutic climate that was respectful, empathic, rewarding and increased Jack's self-confidence.

Jack reported to enjoy drawing in his spare time and I viewed the best way in which he could discuss the offence in some detail with another person would be by drawing a storyboard of the situation that led up to and followed the act of abuse. The actual abusive acts are not drawn as such. It was limited to 8 squares- the idea behind this is to prevent the situation where the offender could extend the exercise to several sheets of flip chart before the actual issues are addressed. Jack kept the storyboard to one page; therefore, the whole offence was always in clear view of him and myself. As the practitioner I was able to make reference to all aspects of the offence in the session. The storyboard was completed over a number of weeks out with 1:1 slots. Each week in session Jack added to his drawing and witnessed the way in which it progressed. He understood the purpose

of this type of exercise was to help him be aware of his actions and thereby prevent its recurrence. In sessions I focused on the 'what' and 'how' of the offence depicted in the storyboard and I also encouraged Jack to articulate what he would put in thought bubbles, heart bubbles and speech bubbles to expand on the nature of the information beyond that of simply establishing actions. By highlighting the fact that there is interplay between thoughts, feelings and actions in the lead up to the offence this helped establish the fact that Jack could have intervened in the process to prevent the abuse.

Assessment of progress

Treatment impact was assessed by re-visiting the four steps of the Finkelhor model and relating what was said in therapy sessions to these component parts to establish whether Jack had begun to acquire any intellectual insight.

Step 1: '*Wanting to'* The extent of detail I obtained from Jack suggests that prior to commission of the offence he had been masturbating in his room earlier that evening with the music channels on for entertainment. Jack recalled being in a good mood. He added that he usually spent nights unwinding in this way. Sometime later, Jack's sister entered the room he shares with their brother and asked Jack to watch a DVD with her and the victim. Jack informed he was unable to play it on his brother's X-box and suggested that instead the three could watch what was on the television. Jack claims that the victim and himself viewed the TV from his brother's bed and his sister watched it on Jack's bed. Jack reports he began to have

sexual thoughts about the females in the music videos on TV and became aware of feelings of arousal.

Step 2: *'Making it OK'* He also offered that he was fantasising about having penetrative sex with the victim and this was strengthened by thoughts at this time including 'Do it' and he imagined that that he would feel on an equal footing with other people his age who had already lost their virginity. Jack acknowledged to himself that if he did have sex with the girl that it could result in his arrest because she was 'too young' for him. That said, it would appear that Jack paid greater attention to thoughts including 'I think she wants it' and 'I heard she did it with her own dad', which increased his sexual arousal and enabled him to move towards commission of an offence.

Step 3: '*Getting the chance'* Jack stated that his sister became aware of the close proximity between himself and the victim and questioned him on it. He responded that he wasn't doing anything. Of note is information disclosed in the victim's statement that at this time, Jack repeatedly told his sister to go to sleep. Jack asserts that when his sister had gone to the bathroom it was at this point the offence took place. It is not known how long Jack's sister was absent however that fact that she was gone for a time meant that Jack did not have any obstacles as such in gaining access to the victim.

Step 4: *'Making the person go along'* Jack has not disclosed anything about how he made the victim comply and allegedly remains bewildered himself about his actions.

Discussion and Recommendations

This was a discrete piece of work which aimed to provide information on the level of risk related to inappropriate sexual behaviour and provide a context in which the client could view the sexually abusive behaviour. Within the time-frame of the case study only very specific aspects of the client's problem behaviour could be targeted as the intervention needed to be pitched at a slow pace with repetition being a key element. However, as has been stated, this client has multiple treatment needs and given that he is 8 months into a 5 year long period at the learning disability hospital there is sufficient time for work to continue on a longer term basis to address other important issues which are outlined later in this section.

Jack engaged enthusiastically in the assessment process and expressed motivation to cease offending. Jack's acknowledgement of the existence of some of the risk factors is a fundamental step which may help him to manage his risk. However, he requires help to develop suitable strategies to minimise and manage these risk factors.

Based on the information obtained from psychological assessment it is recommended that the following areas are covered in treatment (a) the individual/ self (e.g. internalizing difficulties), (b) relationships (e.g., social skills, externalizing problems with peers and family), and (c) sex (e.g., sexual knowledge, sexual abuse, specific psycho-education). All of these factors could reasonably be covered in a manualised cognitive- behavioural treatment programme delivered in a group setting or offered one to one.

It is noted that it took a substantial amount of therapeutic effort in the beginning stages to overcome Jack's 'vague' response style; this may reflect

a shyness in him and it is not known whether, if Jack were to be placed into a sex offender treatment group, he would assume this particular presentation once more as a way of coping with the unfamiliarity of it. On the basis of past experience with Jack I am inclined to think that he would be more amenable to positive change by continuing to work with a psychologist on one to one basis. It is acknowledged that resources do not always permit offence focused work to be offered to each individual and it is important that whoever carries on this work with Jack actively demonstrates positive therapist characteristics (warmth, empathy, rewarding, and directiveness) to generate an effective therapeutic alliance, and to assist Jack in believing he can actually benefit from intervention.

Within the treatment programme (group or individual), attention should also be given to holistic lifestyle improvement rather than simply rehearsing strategies to deal with offence-related risk factors, as the latter approach has proven ineffective in the past. For example, Jack should be encouraged to practice ways in which he could build social relationships and to identify simple activities that he will find enjoyable and diverting.

It is apparent that Jack has had experiences in the past where he has found it difficult to express himself honestly and openly. To this end, Jack is encouraged to learn assertiveness skills and appreciate how this type of behaviour contrasts with other options including being passive or aggressive. In sessions he should be provided with opportunities to practice this skill when dealing with interpersonal problems.

Evaluation of the initial intervention highlighted that Jack externalizes responsibility for the index offence (i.e., blamed the victim). There are other

cognitive distortions within his account and these too should be considered a treatment target in a subsequent intervention.

At the outset when Jack was in denial, it was suggested to Jack that it may have been something about his behaviors, attitudes, thoughts, and feelings within the situations that led to the conviction, and may therefore lead to more allegations in the future unless he is able to modify or manage them. In the intervention to be provided Jack would benefit from being taught to recognize warning signs and high-risk situations which lead to an offence with the goal being to avoid or manage these situations.

Jack's treatment ought to include material that helps him to develop an understanding of the contextual and psychological factors that together resulted in him being convicted (e.g. sexual themes in the media). Related to this is the need for more information regarding the role sexual fantasy played in his offence pathway. If Jack develops insight into these conditions, the focus of treatment can then be on supporting him to develop plans and strategies that would prevent him from getting into the psychological state, or situational circumstances, where he could be accused again.

Part 2: *Family Intervention*

I was keen to provide an intervention for Jack's family which included a psycho- educational component and a supportive element, to mitigate against feeling excluded from their son's care and treatment. I proposed this idea to my placement supervisor, who reported no family work had been carried out at the hospital before, although because of her belief in the positive impact increased family involvement can have, and that the plan could be viewed as an extension of my work with the client, consent was given to undertake carer support sessions.

Both of Jack's parents and his maternal uncle consented to and attended parallel therapy sessions co-facilitated by myself and a staff nurse, between February and July 2012. Sessions were scheduled fortnightly on average, and the amount of sessions offered was influenced by the family's ability to attend. A room in the hospital provided a quiet and comfortable environment in which the meetings took place.

I hoped that by communicating with the client's family in a supportive, informative and caring way this early on in the client's admission, his hospital experience and everyone's adjustment would be improved.

The aims of the sessions provided to Jack's family were as follows:

- To create a rapport with the family members.
- To identify and value the role of the family and encourage the maintenance of relationships between them and the client.
- To provide information on how families of forensic service users can receive more support and help.

- To provide family members with knowledge and understanding of explanations for sexual abuse.
- To gain an understanding of the intervention work the family member will likely be provided at the unit.

The psycho-education focus of the sessions involved providing information to validate and normalise experience, promote knowledge acquisition, and foster understanding. These were used to contextualise sexual offending. The main objective was to promote engagement in a non-threatening way and provide a foundation onto which proper family therapy sessions, if they are offered, could build.

Client Profiles and Engagement

Jack's father and Jack's mother lived together with their large family. Jack's uncle lived a short distance away in a home which he shared with Jack's grandparents. Mum, who was not in employment, reported that her family was very close and they go everywhere together. At the time of participating in the group sessions with the psychologist, Jack's father was absent from work through sickness, and was at home with the family. Jack's uncle was also in paid employment and accepted Jack into his home following arrest for the index offence.

Jack's family successfully attended all scheduled appointments except one due to hospitalisation of another family member. On this occasion, Mum telephoned in advance to explain her circumstances. Sessions usually lasted 1 hour from the point of arrival. It is noted that despite the family agreeing from one fortnight to the next when and what time of day they would be able to attend the group sessions; it was rare for them to be on time.

Jack’s mother said that her motivation for attending carer sessions was to stress the importance she attached to staff working with Jack and by the end of the family support sessions she had hoped that Jack would disclose the details of his offence. Mum strongly indicated that she valued staff involvement and as a family they wanted to ‘come alongside’ professionals to learn about the intervention work Jack would likely participate in whilst living at the hospital. Jack’s uncle expressed anxiety at the outset of the family therapy about the consequences for Jack if he did not fully understand or appear to be making progress. The family acknowledged that if they didn't know what types of things Jack would be asked to work through as part of his treatment, that they might unwittingly be sending him a different message and that this would not help him when he is permitted to leave hospital.

Mum participated actively in the sessions, whereas Dad rarely spoke unless specifically addressed. Jack’s uncle had a tendency to use psychology meetings as an opportunity to ask other things that had been discussed previously at ward round but the outcome of which he didn’t appear to like (for example, querying how long supervised visits would carry on for). Jack’s uncle typically presented to the psychologist in a hostile manner. The reason for this remains unclear, however, his negative feelings about the therapy sessions and in particular the psychologist were made known to managerial staff who work in the Learning Disability Hospital, where the client was detained. As per the advice of my placement supervisor, carer appointments continued to take place whilst Jack’s uncle sought to communicate his frustrations to hospital management and after some adjustments were made to take into consideration existing family

responsibilities, desired length of sessions, location for meetings and frequency of contact with the psychologist, the atmosphere became more conducive to meaningful engagement and a therapeutic alliance was loosely established.

The family had been provided with a booklet called 'Protecting Our Children a Guide for Parents.' Jack's Uncle requested information on the models/framework which I used with Jack as part of the assessment process. General information was relayed to them when it was appropriate to do so, without breaching client confidentiality, about how Jack was responding to different assessment pieces.

After 5 fortnightly sessions Jack's mother and father advised they had been referred to a psychologist by social services. They were encouraged to view the timing of this as a positive thing because, owing to the end of my placement at the hospital, the carer support sessions were drawing to a close. Jack's uncle was not included within this clinical psychology referral however reported that he did not see what good it would do him.

Evaluation

In order to assess the acceptability of carer support sessions and gather experiences that might be important to the ongoing development of these, feedback was sought from the client's family. The family indicated that they found the meetings useful and that the materials provided to them were accessible and user-friendly. Family members reported having learned new information about their son/nephew. All persons reported never having received this type of information before. What family members said they appreciated most about the meetings related to (a) information exchange:

information about client care and how things work on the ward (b) Establishing links: meeting the people responsible for the client's care (c) Being heard: being able to discuss feelings (d) Questions answered: that staff are prepared to listen and answer questions.

The nursing staff member involved in the work as a co-facilitator reported a number of benefits of taking part. He advised that information obtained from the family helped fill the gaps, particularly around risk factors leading to the client's index offence. Furthermore, he stated that being involved in these meetings gave him the opportunity to develop a better rapport with the family, provide reassurance to the family regarding any concerns, and enlist their support (i.e. relapse prevention and risk management).

If I were to have a further opportunity to work with families of offenders in the future, I would review the timing and delivery of the sessions. I think it was beneficial that the first session took place close to the time of the client's arrival (1 month after admission), and therefore would continue with this next time, however I think subsequent sessions may be best undertaken once other aspects of the individual's treatment have been completed. This might assist the information-gathering process for staff and help the service develop a positive alliance with the family from the outset, while simultaneously providing families with an understanding of sexual offending and a formulation of the nature of the individual's strengths and needs over a longer time frame. Later sessions could include relapse prevention and be offered prior to discharge.

This program was not designed to replace or remove the need for family therapy intervention and it is possible, as occurred with the family in my

case study, that referrals to specialists will be an important aspect of treatment for some. It is hoped that Jack's family will continue to foster an improved relationship with him as he continues to participate in assessment of his needs. It is also hoped that further professional input from the multidisciplinary team will be offered to the family at later stages of Jack's treatment and that the wider family will positively engage with this support. With the positive findings of this case study, perhaps the learning disability sex offender assessment centre may be able to extend the availability of this resource to other forensic carers and undertake some formalised research relating to its impact.

Chapter 4: PSYCHOMETRIC CRITIQUE

Critique of The Bene- Anthony Family Relations Test

Abstract

This chapter describes the Bene-Anthony Family Relations Test and background to its development. The validity of the test is limited by the content of some items and their categorization, though there is evidence that the test can distinguish between populations that differ on other related variables. The reliability of the Bene-Anthony Family Relations Test is limited by the child's use of language and concept of family. As such, the test is not sufficiently robust for use in research. Nevertheless, the Family Relations Test seems to be the only instrument available that can explore the perceived emotional context of family relations, and it has provided a useful way of engaging with children early on in assessment, or when they find verbal expression difficult. This review suggests that there is a place for an instrument that assesses the child's perception of the emotional quality of family and peer relations. Recommendations for the development of a test that reliably assesses the child's perception of the emotional content of relations are reported.

Introduction

The Bene-Anthony Family Relations Test (FRT) is a projective test that assesses the child's perception of family relations. Eva Bene, a psychologist and James Anthony, a psychiatrist, first published the test at the Institute of Psychiatry, London in 1957 (Bene & Anthony, 1957). It has since been revised (Bene, 1978) and reprinted (Bene, 1985).

The FRT was developed at a time of two converging philosophies in child psychiatry and psychology. One was the use of projective techniques in the assessment of a patient's emotional perception and interpretation of the world. The other was a growing recognition of the need to view the child, who had been brought to the clinic as the identified patient, in the context of the family and that the problem may not lie solely in the child. As a projective test, the FRT attempts to provide a structured way of capturing these perspectives, but it remains an interpretive endeavour rather than a standardised psychometric instrument (Semeonoff, 1976).

The quality of family relations influences psychological development in childhood and has an important role in the aetiology of childhood psychiatric illness (Dunn, 1994; Garmezy & Masten, 1994). Studies and models of relations within families have emphasized the importance of reciprocal interactions between family members (Hinde & Stevenson-Hinde, 1988; Minuchin, 1974; Patterson, 1982). Instruments to assess family function derive from such models and usually focus on behaviour or roles. However, affective relations may be more consistent when compared with other variables such as cognitive style (Martin, 1975), and predicts family functioning (Jacob, 1975).

Most measures of children's relations with other members of their family or peer group depend upon observations made by adults, usually parents/carers, or professionals. The risk of childhood psychiatric disorder is specific to the child's experience of interpersonal relations (Jenkins & Smith, 1991; Plomin & Daniels, 1987). Therefore, a description of childhood relations should include the child's perception to have clinical significance.

This review focuses on the FRT which is one instrument that assesses affective relations from the child's perspective. Two adult versions, including a married couples version, are also available (Bene, 1976), but not included in this review. This review examines the identified psychometric assessment in terms of its scientific properties and its research uses.

Overview of the tool

The Family Relations Test was devised to measure the emotional attitudes of the child to family members and his view of their feelings towards him (Bene and Anthony, 1957).

The user qualification requirement specified by ACER is category P: 'professionals who are registered as psychologists or hold qualifications that would allow registration (plus) psychology students under supervision'.

Although the rationale of the test accords with psychoanalytic theory, its use has not been confined to any particular school of psychological thought (Meyer, 1963; Frost, 1969; Kauffman, 1970; Roche, 1970.

Some reservations have been expressed about its suitability for adolescents, but it is highly regarded for use with younger children (Chazan, 1970). Other measures, such as the Pickford Projective Pictures (Pickford, 1963), the Family Relations Indicator (Howells and Lickorish, 1962), or the Jackson Test for Family Attitudes (Jackson, 1952) require speech, unlike the FRT, where talking is not essential: statements are read aloud by the tester, though older children may read for themselves. A particular feature is the relative simplicity of the task, which permits its use with very young children. The test manual does not stipulate a minimum age for testing and much may depend upon intelligence and personality.

The test material consists of 20 cardboard figures, ambiguously drawn, representing people of various ages, from grandparents to a baby in a pram, and with a posting box attached to each. The test begins with the following instructions to the child:

We are going to play a game of pretence.

Do you see all those figures standing there?

We are going to pretend that some of them are the people in your family.

Which one do you think could best represent your Mum?

Now which one do you think could best represent your Dad?

Which one would you like to be yourself?

The child continues in this manner until he has chosen a figure to represent every member of his/her family. His choices may reflect his emotional life, rather than the nominal structure of his family; for example, he may exclude a parent or sibling not resident in the home, or with whom he has

little interaction, and include unrelated individuals who are resident or with whom he has frequent contact.

An additional character, Mr. Nobody, is then added to the selected group. Mr. Nobody is represented by a man dressed in a raincoat and hat with his back turned, to whom the child posts cards that do not belong to any family members. The placement (projection of feeling statements) into the character box Mr. Nobody by children is like filing these statements into the 'personal unconscious'. As Jung (1959) states 'the contents of the personal unconscious are chiefly the feeling toned complexes; they constitute the personal and private side of the psychic life (Jung, 1959, p.4). In this broader view, the figure box is not simply regarded as a repository for repressions or for forgotten or subliminal impressions, but as an undifferentiated energy containing good and bad elements.

Each figure box has a slit at the top and the test items (emotional attitudes) are printed on small cards. Each statement is defined by three parameters: its valency, strength, and direction. The valency of the statement is defined as either 'positive' (for example, 'I like to cuddle this person in the family'), or negative ('I hate this person in the family'). The strength of the statement is defined as 'mild' or 'strong'. The direction is either 'outgoing' ('I like to hug this person'), or 'incoming' ('This person likes to hug me').

There are two sets of cards, one designed for use with children up to 8 years old and a longer series for older children and adolescents. The version for younger children contains 40 items. In the younger version, the statements are phrased such that the examiner sits alongside the child and addresses the figures, referring to the child in the third person, for instance 'N . . .

loves you. Whom does N. . . love?' (where N. . . represents the child's name).

The older version consists of 86 cards including a selection of cards which describe *parental overindulgence* (for example, 'This person in the family father/mother spoils too much'), and *maternal overprotection* ('Mother worries that this person in the family might get ill'). The card statements with mild positive attitudes reflect feelings of friendly approval, while the mild negative attitudes reflect unfriendliness and disapproval. There are 10 mild positive and 10 mild negative statements coming from the child (outgoing) and 8 mild negative and 8 mild positive statements going toward the child (incoming).

The stronger positive attitudes are somewhat different in that they express more sexualized or sensualised feelings associated with close physical contact and manipulation; for example 'I like to kiss this person in the family'; 'I like to tickle this person in the family' (outgoing) or 'this person in the family likes to cuddle me'; 'this person in the family likes to be in bed with me' (incoming). The negative strong feeling statements clearly express hostility and hate. Such items are: 'Sometimes I would like to kill this person in the family' (outgoing) and 'This person in the family makes me feel afraid' (incoming). There are 8 strong positive and 8 strong negative feeling statements coming from the child and an equal number going to the child.

There are 5 items expressing maternal overindulgence, 5 items expressing paternal over-indulgence and 8 items expressing maternal overprotection. There are no cards that describe paternal overprotection.

The child is asked to 'post' the card into the box appropriate to the person whom it seems to fit best. If the child feels that the statement does not apply to any member of the family it is posted to Mr. Nobody.

When the child is handed the emotional statement several internal processes take place (1) imagining: imagining the feeling that the statement suggests, the appraising process is stimulated; (2) interpreting: experiencing, projection; to whom does this statement belong? (3) will: action; placing the card statements in the appropriate box.

Step one is a simple procedure for the child since the emotional attitudes printed on the cards are general enough for any child to form a frame of reference. Step two has a paradoxical nature; the child adopts the line of least resistance, i.e., he does what he/she feels like most because play is connected with pleasure (Bruner, 1976). In this instance the child can truthfully identify to whom the statement belongs, or he/she can wish that the item belonged to a certain individual; (idealization occurs when the child uses an exaggerated number of positive items for members of his/her family while placing most negative ones into Mr.Nobody). He/she can deny the identity of the person to whom the statement belongs; (denial occurs when the child has placed most positive and negative items into Mr.Nobody; displacement occurs when he/she has given most items to peripheral rather than to central figures). This last option can be a result of feelings which the child recognizes and does not want to express or an unconscious defence against recognition. In step three of the projective situation the child is again faced with the paradoxical nature of the situation for in play (games) there is a code of honour and fair play (Piaget, 1965). It is demanded of the child in this step to follow the line of greatest resistance;

it is hoped that the child will subordinate him/herself to the rules of the game and renounce his/her impulse to lie and/or deny true feelings, thus maximizing pleasure in the play situation (Piaget, 1965). In either case with step two and three the truthfulness of the child's 'psychic reality' will be expressed. The imaginary play situation and reality coincide.

The examiner counts the cards 'posted' and calculates 'the psychological importance of each family member', that is the total number posted to each; Bene and Anthony (1957) suggest that normally the distribution of responses should be: mother, father, siblings, and others in descending order of emotional involvement. Furthermore, there should be evidence of belief that others reciprocate the feelings which he holds towards them. Empirical support for these hypotheses is provided by Linton et al. (1961) and Turner (1977). In addition, the administrator notes the following (a) 'egocentric responses', that is the number and valency of cards given to self; (b) 'ambivalence towards family members', defined as when the sum of neither the positive nor the negative items exceeds two-thirds of the total; (c) total 'outgoing and incoming feelings'; (d) 'the probable defence mechanisms used during the test', which may be interpreted from the distribution of cards, for example if several cards are given to Mr. Nobody then the child may be using denial; (e) 'test inhibition/disinhibition', a measure of the child's avoidance of the expression of conflict, for example giving cards of a similar type to more than one person, thus diluting their effect.

Reliability

Reliability refers to how consistent a study or measuring device is and is a vital component of a trustworthy psychological test. There are two types: *Internal Consistency Reliability* refers to how well all the test items relate to each other; *Test-retest Reliability* refers to how well results from one administration of the test relate to results from another administration of the same test at a later time.

None of the usual methods of assessing the reliability of a test is quite suitable for the FRT. If the test-retest method is used with a short interval the child may be influenced when tested on the second occasion by his memory of the first occasion. If this method is used with a long interval then it is reasonable to expect changes in both the home environment of the child and in the maturing child himself. This is especially true is the case of hospitalized children who are in therapy and whose mothers are in contact with mental health professionals.

The split-half method, a measure of consistency where a test is split in two and the scores for each half of the test is compared with one another, is also unsuitable for this test, since the items within any area are not sufficiently homogenous and since the number of choices the child can make with regard to each item varies from case to case. However, Anthony and Bene (1957; republished Bene, 1985) made an attempt at using a modified form of split-half reliability using a clinic sample of 76 children in the following way. The test consists of 86 items, each of which could be allotted to Mr. Nobody, self, father, mother, various numbers of siblings and others in the family. Out of this, by a combination of items, three types of scores

were used. Positive feelings, to and from, combined - 34 items, Negative feelings, to and from, combined - 34 items, Overprotection and overindulgence combined – 18 items. Separate reliability coefficients were obtained from each of these scores for each of the people in the family, regarding each score as if it were the result of a separate test. Within each score two sub-scores were computed, for the odd and for the even numbered items respectively. Only figures to which children posted six or more items were selected. Thus, for each child, there were two separate sub-scores for positive feelings in relations to Father, two separate sub-scores in relation to Mother, and so on. The number of children who gave 6 or more items to the self, second or third mentioned siblings and others in the family was too small to warrant computation of a coefficient. The corrected split-half correlations ranged from r = .68 to r = .90. Whilst the FRT manual concludes that the observed values seems to indicate that the FRT is reasonably reliable, the methodology used in this study limits the interpretation of its results.

Roche (1970) estimated reliability by comparing three techniques of administration (standard, issuing four copies of each card, and presenting only two family members plus Mr. Nobody simultaneously - repeating the test a sufficient number of times) at 10-day intervals on 20 children aged 7 years from intact families with two siblings. No significant difference was found between the standard and multi-card techniques. The child's mother received significantly more cards in the paired-technique method. The sample size, specific population studied, and use of non-standard techniques limit how far these findings can be generalized.

Kauffman, Weaver and Weaver (1972) studied test-retest reliability at a 3-week interval in a sample of 41 boys and 5 girls, aged 8–16 years, of normal IQ who enrolled on a voluntary remedial reading programme. The overprotection/indulgence items and all items posted to self had low correlations, and the correlation of other items ranged from r = .304 to r = .900. However, no firm conclusions can be drawn as no correction was made for the number of correlations studied.

Validity

The validity of a test is the degree to which it measures what it claims to measure. There several ways to estimate the validity of a test including *content validity, concurrent validity, predictive validity* and *construct validity.* When a test has *content validity*, the items on the test represent the entire range of possible items the test should cover. *Concurrent Validity* occurs when the criterion measures are obtained at the same time as the test scores. This indicates the extent to which the test scores accurately estimate an individual's current state with regards to the criterion. *Predictive Validity* occurs when the criterion measures are obtained at a time after the test. A test has *construct validity* if it demonstrates an association between the test scores and the prediction of a theoretical trait.

Kauffman (1970) assessed the content validity of the FRT. He found no rationale for the selection or categorization of the items. No study has assessed professionals' views of the validity of each item or of how they are grouped. Some items describe an emotion, some a behaviour, with or without an emotional content, and others a desire. The FRT manual does

not distinguish between these categories. Instead, each result is a sum of these disparate items.

With regards concurrent validity, Parkin (2001) states there is no 'gold standard' against which to compare the FRT. A comparison with other assessments purporting to measure the same construct (family relations) may be confounded by any 'true' discrepancies between the child's perception and that of the clinician or parent, which may indeed be of clinical and aetiological importance. That said, Anthony and Bene (1957; republished in Bene, 1985) compared FRT results with observed and reported family relations. The results were inaccurately significant (Jensen, 1959), and numbers were too small to draw firm conclusions. Later studies compared the FRT with clinical findings (Meyer,1963), the Rorschach (Lingren, 1968) and the Lowenfeld World Technique (Meyer, 1961). Again, sample sizes in these studies were too small to be considered further.

The criterion validity of the FRT can also be determined by its ability to discriminate populations that differ on a variable independent of the test, and between which the test would be expected to discriminate based on other evidence or theory. For instance, the test may distinguish between populations with and without mental illness. Two assumptions are made here: (1) children with mental ill health differ from those without in how they view family relations, and (2) the test contains items that measure family relations that are not influenced by extraneous variables. Parkin, (2001) indicates that 41 studies have used the FRT to compare children from populations that differ in some way. The full text of four of these is unavailable in English (David, 1990; Kosecka, 1999; Marcheschi, Tosi, Morelli, & Palacio-Espasa, 1999; Zajaczkowski, 1998). Of the 37 studies in

the English language, 19 reported significantly different FRT scores between populations, which included all seven studies of children with emotional or behavioural disturbance. A further 15 studies suggested non-significant trends. A more detailed analysis of these is limited by the variation in purpose, design, populations, and levels of significance across these studies. The ability of the FRT to distinguish between some populations supports its predictive validity in these populations, with reservations regarding its content validity.

Uses in research

The FRT has been used to compare different populations (discussed above on validity), to assess outcome and assess childhood relations in particular circumstances, such as child abuse.

Cullen (1976) used the FRT as an outcome measure in a study of 124 children, whose parents received 12 workshops on child development over 6 years, and 122 controls. Children in the experimental group posted more positive, negative, and dependency items to mother after intervention. There were no differences in items posted to father. Skuy and Solomon (1980) also used the FRT as an outcome measure in 36 children of normal IQ who had a specific learning difficulty, to compare three possible interventions: individual counselling plus a parent group, individual counseling only, and no intervention. There was a non-significant trend for children whose parents had attended the group to post more positive outgoing items and fewer negative incoming items to mother than pre-intervention.

Geddis, Turner and Eardley, (1977) recommend the FRT as a useful 'way in' to family dynamics in abused children and a means of 'firming up' evidence of abuse. Hyman and Mitchell (1975) reported its use with physically abused children.

Discussion

There has been a noted decline in the popularity of the FRT since the 1970s. There may be several reasons for this, which broadly includes advances in assessment since the FRT's publication and specific qualities of the test that have come into question.

Several theories and studies have influenced the assessment of childhood relations since the FRT was introduced, and the use of projective techniques has been criticized. Attachment theory, first described by Bowlby (1969), concerns the interactions between the infant/child and (usually) the main caregiver that are regulated with the primary purpose of optimizing the child's survival and development. Four patterns of attachment have since been described (Ainsworth et al., 1978; Main & Solomon, 1986). These are of clinical significance and may represent personal internal working models (Main, Kaplan, & Cassidy, 1985). The nature of attachment predicts future psychopathology (Lewis et al.,1984) and relationships (Troy & Sroufe, 1987), and may influence how children regulate emotions (Cassidy, 1994). The child's inner concept of the emotional content of relations may be an important link between attachment and the development of psychopathology. However, Parkin (2001) states that no published study has explored this to date.

The FRT was published at the time of the development of personal construct psychology (Kelly, 1955). People hold beliefs, or constructs, about each aspect of the world and constantly test the validity of these constructs 'scientifically'. Ravenette (1977) described methods to elicit children's constructs and their clinical application. Instruments attempt to standardize such constructs, indicating the necessity of assessing children's understanding of them. There is no evidence published on this with the FRT (Parkin, 2001).

Specific concerns about the test may also have contributed to its reduced use. Researchers have reported being unable to make meaningful analyses (Fielding et al., 1985; Golombok, Cook, Bish, & Murray, 1995). Also, the timeframe is unclear: the child may refer to the previous few minutes or a period of several years. This may vary between children or between questions. This is neither standardized nor commented upon in the manual.

The valency of an emotion cannot be assumed to be stable. For instance, anger may be viewed as a negative emotion most of the time, but may also be used in a positive way (Bodenhausen, Sheppard, & Kramer, 1994). The stability of the valency of behaviours such as cuddling, tickling and teasing cannot be assumed. Items such as '. . . likes to tease me' are scored negatively. However, children may also construe teasing positively if their experience of it has been safe, contained, and enjoyable (Pawluk, 1989; Shapiro et al., 1987). Teasing has an important role in social development. Thus, the emotion is 'contaminated' by using behaviours to define it.

Each category of items in the test is also heterogeneous, containing phrases that refer to behaviour, behaviour with emotional content, emotions, and

desires on the part of the child, with no distinction made between these. There is no evidence in the manual or associated literature to support the definitions of ambivalence, types of defence used or test inhibition/dis-inhibition. Several studies have demonstrated that the FRT can discriminate between populations that differ on other variables, but the basis on which it does so remains unclear. Early studies on the reliability of the FRT were methodologically flawed and, therefore, little weight can be given to their findings, and no further studies have been undertaken. Thus, the items in the test are heterogeneous, arbitrarily defined, and not categorized according to a definable schema, and the validity and reliability of the FRT are in doubt.

The clinical importance of childhood relations was discussed in the introduction, and extends outside the family to include peers (Dunn & McGuire, 1992; Parker & Gottman, 1989). However, the FRT does not include peer relationships: items contain the phrase 'This person *in the family* . . .'.

The paradox of this psychometric tool is that psychologists have positive views about the FRT, regarding its use in practice which, rather than being a research tool, is used as a means of engaging a child before further exploring the child's 'inner world'. It seems to be the only instrument available that can explore the perceived emotional context of family relations and it has provided a useful way of engaging with children when they find verbal expression difficult.

Conclusion

The FRT can provide an important insight into the child's perspective of family relations. However, the test is not sufficiently robust for use in research: its reliability and validity have not been convincingly demonstrated, and comparative analyses are not always possible. However, some clinicians use the test to provide formal evidence of the child's wishes or as a useful 'way in' to the assessment of children who find it difficult to express themselves verbally. Instruments are available that assess behaviour and roles in families and peer groups, but none specifically assess the perceived emotional content of family and peer relations. Further exploration of the importance of these affective relations requires an instrument that is acceptable to children and reliably identifies their perceptions. Parkin (2001) makes suggestions for developing such an instrument and lists the following to be taken into account: (1) children's perception of relationships can be assessed; (2) focus should be on the emotional components of each relationship; (3) it is practical to consider the complexity of childhood relationships by assessing serial dyadic relations; (4) the relations assessed should at least include close family members and significant members of the peer group such as friends, with clear definitions of inclusion and exclusion; (5) the child's responses about one person should not limit their responses about other people; (6) children should be able to make use of the test irrespective of ability or specific disability; (7) figures or graphics should be as neutral as possible; (8) the language should be simple, unambiguous and, as far as possible, common across cultures and sub-cultures; (9) standard administration of the test should be defined, as should training requirements. Parkin (2001) does not

want the limitations of the FRT to wash away the stated awareness of its strengths, noting that it could be adapted and improved as a computerized assessment device. A 'new generation' test that assesses the child's perception of the emotional quality of family and peer relations is being developed by Parkin to meet the criteria listed above.

Rationale for use of this psychometric within the case study.

As was discussed in the preceding chapter, at one of my forensic psychology practice placements, I carried out an assessment with a learning disabled adolescent who had sexually offended. The client had required speech and language therapy and special assistance at a mainstream school. Upon meeting the client soon after he had been admitted to the sex offender unit, I observed that despite the earlier support he had received regards these communication deficits, the client continued to present with limited speech, and when he did speak to myself or others, it was at a level similar to that of a young child. The client's performance in language as assessed by the CELF-IV (UK) (Semel, Wiig, and Secord, 2003) yielded age equivalence ranging from 4 years 6 months to < 9 years. Comparing this to his chronological age of 18 years highlights his deficits in language. Knowing that I was tasked with carrying out a piece of work with this individual, and acknowledging that the standard assessment methods would in all likelihood, be inappropriate for this client, I considered that he may be encouraged to respond through using something like a play interview. Use of The Bene-Anthony Family Relations test prove to be a most effective way to elicit information and to discover his perception of feeling towards various members of his family, as well as to estimate his perception of family member's reciprocal regard for him. This fairly non-threatening interview task was a helpful way to approach the information gathering phase of the interview and an enjoyable, novel process for myself.

Chapter 5: DISCUSSION

Discussion

In the introduction section of this thesis I reviewed relevant studies and argued for the importance of the current research study. The introductory chapter highlighted the impact of having a family member with mental illness on family carers. It was reported researchers have attempted to measure this impact in terms of burden, by developing a variety of scales in an endeavour to quantify this phenomenon, while also appreciating its subjective nature. The point was made that such positivist approaches do not allow for an in-depth exploration of the experience of having a family member with mental illness or acknowledge the complexities of this phenomenon for the individual. The majority of published research to date has focused on families in the role of being an informal carer, particularly in the recognition that it is most often parents who take on this role for their mentally ill adult children. Research has correspondingly investigated the needs of family/ parent caregivers. In the introduction the assertion was made that the experience of having a family member with mental illness cannot be reduced to the notion of being a carer, neither can such experience be objectified in terms of definition and meanings as prescribed by the scientific community. A qualitative phenomenological framework was considered most appropriate to explore this experience. The narrative literature review revealed that studies into the experience of having a relative detained in forensic services are scarce. These studies referred to have largely used survey approaches, or interview data, which is then quantified in terms of pre-determined categories. Other studies have obtained data from healthcare professionals rather than from families themselves. It was considered necessary and timely to add to the

knowledge base on family carer involvement in forensic services, focusing in particular on understanding the experiences and needs of parents who support individuals in forensic (secure) mental health services. Eliciting views from forensic caregivers themselves may inform professionals about factors related to sustained caregiving and help to identify points of effective intervention for families in this context.

Summary of findings in chapters 1-4

In chapter one, a structured review and synthesis of qualitative studies was reported, undertaken to develop insight into the perceived level of involvement in care from the perspective of family members of mental health service users and examine family carers' relationships and engagement with professionals. Qualitative studies are particularly suitable for exploring the attitudes, beliefs and ideas informing how an issue is perceived and can capture the lived experience of the respondents (Willig, 2009). It was therefore considered appropriate that studies from any established qualitative research tradition would be suitable for addressing the review question. Included studies focused on understanding how family caregivers of relatives admitted to a psychiatric hospital experience interaction with the mental health care system and evaluation of involvement in care during the subsequent hospital treatment of their relative. Two overarching themes were identified which were deemed important and reflected the essence of what was being reported in the literature. These were: 1) the problem of confidentiality and 2) the need of support.

The findings highlight that the practices of some health professionals contribute to the distress experienced by caregivers. Parents in the included

studies spoke of the exclusionary practices of health professionals and of not being listened to, or valued. Many family caregivers believed that their assessment of their relative's mental state was valuable, but that this view was not held by the professionals. Health professionals' application of the principles of patient confidentiality resulted in parents being provided with very little information about their mentally ill loved one. Parents reported that while they respected the need for confidentiality in relation to their family members' personal life, they believed that they should be routinely provided with information that impacted on their ability to care for their relative. Parents viewed that the mental health difficulty experienced by their family member impacts on the entire family and consequently they should receive support to help them manage in this situation. Helpful as it is to synthesise findings from qualitative studies on the subject of collaboration between professionals and family caregivers in general mental health services, the importance of furthering knowledge in this area by considering the lived experiences of forensic caregivers, provided the impetus to carry out an exploratory research study involving this particular caregiver group.

The methodology that best seemed to fit best with my ontological and epistemological position and the research question was Interpretive Phenomenological Analysis (IPA) as developed by Smith (Smith & Osborn 2008). This study, described in detail in the second chapter of this dissertation, employed a qualitative design conducted within the framework of IPA and concerned the experiences of family carers, where the family member is in forensic (secure) mental health services, being looked after by professionals. Sampling was necessarily purposive in order to illuminate

the research question. IPA prioritises depth of analysis over breadth of sample, and most IPA studies have sample sizes in the range of 4-10 interviewees (Smith & Osborne, 2008). Six participants were interviewed to allow for a deep analysis of each participant's responses and subsequently across the whole sample. The parent-child relationship is different from other types of close relationships such as siblings or spouses and the majority of patients in medium secure psychiatric hospitals have either never married or have had a relationship breakdown either prior to or during their admission (MacInnes, 2010; Johnson, 2000). Limiting the study to the experience of parents increased the homogeneity of the sample.

The meaning of parental care for a son or daughter with a mental health problem living in a forensic setting was illuminated in the themes "something's not right"- onset of mental distress; "going through hell"- experiences of violence and entering secure services; "it's a terrible battle"- relating with professionals; and "a very sad fact of life"- caring with no end in sight.

Parents' lived experiences of providing care to a son or daughter compulsorily detained in a medium secure unit is characterised by a strained relationship with mental health services, accompanied by practical difficulties in getting help in the first place, and conflicting emotions felt in response to their unwell family member's admission to a forensic setting. If mental health services do not provide sufficient care for the individual with mental distress, the burden on parents and the intensity of care they need to provide increases. This happens when there is a delay in getting help if a situation is not perceived as urgent, when family caregivers do not know how to contact services and when family members are admitted later (for

example only once their mental health significantly deteriorates). Family caregivers and clinicians can have different views on when admission is required, particularly if this is against their relative's will. For family caregivers this is not just a difference in opinion, but usually also a shift of the responsibility for care towards them which can be experienced as very burdensome. Caregivers are often in a position in which they perceive that patients' needs (e.g. for a least restrictive treatment outside the forensic mental health facility) and services' needs (e.g. for a community treatment because of lack of availability of hospital beds and cost of inpatient care) have more priority compared to family caregivers' needs when they are finding looking after their loved one at home extremely challenging.

Both family caregivers and secure mental health services provide care for an individual with mental health problems at the time when he or she is acutely unwell. But whilst mental health services have a professional role, the caregivers' role is intertwined with their family relationship with a patient/service user. This emotionally laden aspect of their involvement can add to the burden of care.

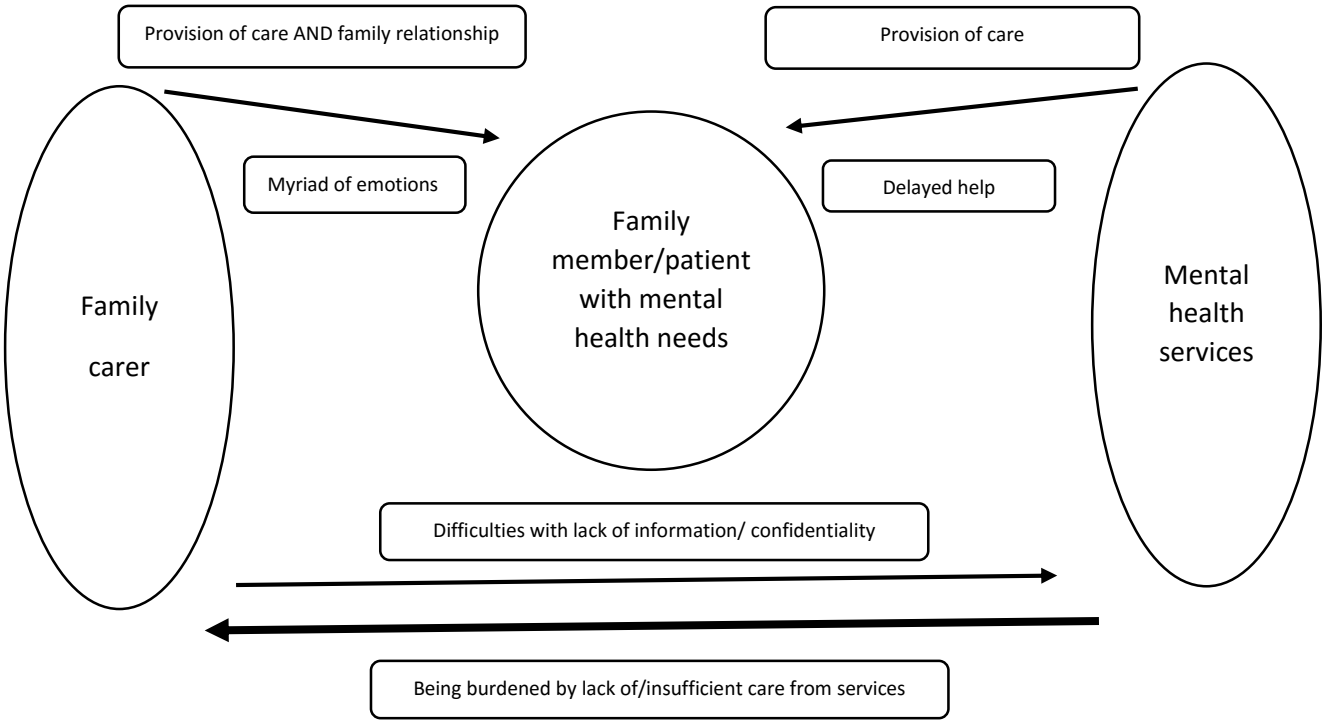
When considering mutual influences between a service user, mental health facility and a family caregiver, it is important to acknowledge that there is a power difference in the relationship between family carers and mental health services as the latter have much more influence in deciding what level of care the mentally ill person will receive and who will provide that care.

The tension in the relationship between family caregivers and mental health services is compounded by difficulties with confidentiality which caregivers see as a right that is not always respected.

This exploratory research study highlights the challenge for clinicians to balance two important tasks that at times can be difficult to accommodate: valuing the important role of family caregivers in the treatment process including the sharing of relevant information with them and the requirements of confidentiality with regard to what the service user has told them. This can be particularly difficult before or during involuntary admission to a forensic secure unit when risks have to be considered which may include specific risks to a family caregiver. In terms of emotional response, in acute situations when an individual's mental health deteriorates so much that a hospital admission against their will is required, the burden of care for family caregivers is extremely high and the feeling of relief once the help is in place is an understandable emotional consequence.

In the collection of parental accounts described there is a risk of disempowerment of caregivers that in this study is illustrated by experiences that family caregivers' opinions and their needs are not being valued in a decision making process, by lack of information and problems with confidentiality. The following diagram (Figure 3) was generated from parents' experiences documented in the systematic review and those of parents' interviewed in the empirical research study.

Figure 3. Schematic representation of family members' experiences of caring for a relative with mental illness and their relationships with mental health services.



In the second part of the included case study (chapter 3) I described a one-off project in which three family carers of an adolescent sex offender client were provided with information and support sessions developed to foster relations between the clinical team and family, and to share information between parties in a structured and contained way. The project undertaken is an illustration of a process by which collaboration between staff and family can be achieved. While it is acknowledged that the carer sessions did not meet the requirement set out by NICE guidelines regarding family therapy provision, the feedback from those who took part suggests that a family based approach to assessment and treatment can assist in decreasing denial for an adolescent sex offender, unify the family and encourage the family members to be a positive resource for one another.

The case study offers a blue print for health and social care professionals in facilitating the more active involvement of families in the recovery/rehabilitation of their family members.

In chapter 4, I critiqued the psychometric measure known as The Bene-Anthony Family Relations Test (FRT) in terms of its scientific properties and its research uses. As a projective test, the FRT attempts to provide a structured way of capturing an individual's perspective, but it remains an interpretive endeavour rather than a standardised psychometric instrument (Semeonoff, 1976). The review concluded that the test is not sufficiently robust for use in research: its reliability and validity have not been convincingly demonstrated, and comparative analyses are not always possible. However, that psychologists have positive views about the FRT, regarding its use in practice as a means of engaging a child, is noteworthy. It seems to be the only instrument available that can explore the perceived emotional context of family relations and it has provided a useful way of engaging with children when they find verbal expression difficult, as was the case for my client, an adolescent sex offender who entered the assessment unit with very limited, hard to understand speech. The Bene-Anthony FRT was a helpful way to approach the information gathering phase of the interview and an enjoyable, novel process for myself.

Systematic review and empirical study limitations

The review may be considered biased as it was conducted by one researcher. Although it is generally accepted that one person is able to conduct a systematic review, it is subject to the opinion of one individual and others may have placed different emphasis on different factors. It was

due to time constraints and resources available, that the author was the only assessor in applying the study inclusion/exclusion criteria to retrieved studies, conducting both the data extraction and quality assessment processes, and deriving themes from the included studies. It is possible that a second rater may have judged returned articles differently, which may or may not therefore have been included in the review. However, a limitation of this could have been the potential for a second assessor to exclude studies from the review, which would have limited even further what was already a small number of remaining articles, perhaps this was a consequence of the author's reasonably tight PICO structure. Upon application of the quality appraisal tool, all studies received an overall positive rating, suggesting that all employed appropriate design and methodology and demonstrated a rigorous and transparent approach to analysis and presentation of findings. Nonetheless, the addition of a second independent reviewer for this stage, and the ones preceding, could have potentially added weight to the reliability of decision making by the sole researcher, and would have enhanced the validity and reliability of the review findings, as well as credibility of review conclusions. If this review were to be repeated, it would take into account these limitations and be amended accordingly.

With the exception of a doctoral dissertation, the review contains only published research. Although the search strategy included unpublished theses and dissertations and no additional unpublished theses or dissertations were found that met the inclusion criteria, that does not mean more research on the review topic does not exist. This may create further

limitations in the conclusions of the review, as it may be a source of publication bias.

Finally, the inclusion of original research articles carried out with varying methodologies that draw upon differing epistemological stances, may be considered a potential limitation in this review. However, such concerns are also queried for the value of being as inclusive as possible when selecting studies for review, as well as the potential to enhance the value of findings when studies of differing epistemological stances are reviewed alongside one another (Finfgeld, 2003; Sandelowski, Doherty & Emden, 1997).

Considering next the limitations of the exploratory research, one criteria for inclusion was that the son or daughter was in regular contact with their parent. This resulted in a sample that was biased towards relatives who had always been loving and supportive towards their son or daughter and continued to have positive familial relationships with their adult child. It may be that patients and family members who declined to participate experienced more intra-familial difficulties and were reluctant to participate in research that might have highlighted these difficulties.

Given that the parent participants had not met the researcher until the time of their agreeance to participate in the current study, this may have produced bias. The opportunity to meet with and build rapport with participants prior to commencement of data collection may have increased the participation rate, as well as engagement with the researcher.

That the empirical study provides a qualitative account of a small and purposive sample of parent carers from a specific area of the UK, makes it difficult to determine the extent to which the findings might reflect the

experiences of parents with adult children in medium secure services nationwide. IPA acknowledges that the findings and conclusions drawn relate to the specific individuals being studied. Nevertheless, the interpretations that were produced for this group of participants may be helpful in terms of *beginning* to understand the experiences of other parents of an adult child diagnosed with a mental illness living in a medium secure forensic unit.

The small numbers of potential participants arising from a single regional service inevitably raised the issue of how their responses could be kept confidential. Any information which might have led to identification of participants or anyone named during the interview was anonymised. Pseudonyms were used in the results section of the study.

This study yielded a huge amount of rich data from the accounts given by parents in the interviews. There were many quotes which could have been used as examples to illustrate the themes and many were necessarily omitted which could have offered further illumination.

While carrying out this research, I was going through a personally difficult time involving an unwell family member and had listened to my parents' accounts as they struggled to get the help they knew their [redacted] (my [redacted]) needed from eating disorder services, and their desperation that something life-threatening had to happen before anyone would take notice. This personal and comparable experience may have impacted on the interview process in that I felt much sympathy towards parents of forensic service users when listening to their struggles, and sensed their frustration with services.

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

Reflections

At the start of the research journey, I hoped that some useful change would follow as a consequence of reporting the perspectives of parents whose children are detained in a forensic care setting. I hoped that the results would influence the development of support services which might alleviate the apparent stress and distress that such parents expressed, leading to better relationships between patients, carers and perhaps even increased job satisfaction among those working in the service.

The medium secure unit where the research idea was borne out of, was my first placement as part of the qualification in Forensic Psychology and provided my first contact opportunity regards families of forensic service users, as before this time, I worked in prisons and rarely did I meet offenders' family members, except if they attended an annual sentence management meeting, even then contact was understandably limited and surface level. I was aware that study participants may have different experiences to those which I was alert to, and wanted to learn from them. My reading of the published literature led me to suppose that loss and grief would likely apply to this forensic population in the same way it is reported by family members of relatives with mental illness, although I was not sure what else might emerge as significant. When I interviewed forensic carers whose family member was admitted to the medium secure unit, I had not foreseen the importance that these parents attached to their child's innocence of any wrongdoing by virtue of their mental health condition.

I had wondered whether confidentiality would be an issue, but this was not something the parents were worried about, presumably because it was

patients themselves who agreed that their parent could be approached to take part in the study, perhaps reflecting a positive parent-child relationship and a level of comfort/acceptance in sharing information. In fact, two fathers in the research study said during individual interviews that both sons wanted their fathers to report back to them later that evening about what the interview was like and what they talked about with myself, the researcher. These two fathers said they had viewed the experience positively and were grateful that it gave them something new to talk about with their sons, also using it as a vehicle to communicate their feelings of affection for them.

I entered the analysis stage with some excitement as to what might emerge, hoping that I would remain as open as possible to themes, including those which might prove to be unexpected. Reflecting on how this may differ for a researcher with limited experience of forensic services, I considered that they may focus on specific issues which arose in the interviews such as offending history, or what a secure unit is like. However, having worked in a children's secure unit and a prison for a number of years after that, all before beginning this qualification in forensic psychology, these experiences allowed me to understand the system within which family members are trying to work. My experiences also allowed me the ability to ask the right questions, to be able to probe more deeply into the answers the parents were relaying to me and my experience also gave me the opportunity to better understand the information that family members were telling me.

Additionally, because of my personal experience referred to earlier (being a [redacted] of a family member with an [redacted]), although not the

same situation as the one researched, there are similarities- I was aware of the difficulties that family carers face, in obtaining the help of mental health services, and of limited resources which restricts the capacity of mental health professionals in working with families.

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

The research process has changed me in that I am more aware of how parents may perceive professionals working in forensic services and that this may be based on their historical experience. It has planted the seed for further study, and possible later qualification in systemic family therapy as before I commenced this doctorate in Forensic Psychology, I was passionate about meeting the needs of offenders, and now having finished this piece of research, I am more sensitised to the needs of offenders' families. It would seem that an effective way to combine both of these interests is through provision of family therapy where individuals are given the opportunity to understand and appreciate each other's needs, build on family strengths and ultimately make useful changes in their lives and relationships.

Conclusion and recommendations

In summary, many parents with an adult child in secure services feel snubbed by mental health professionals, and complain about the lack of collaborative working despite Governmental policy drive for mental health services to work in partnership with families and carers, including within forensic services (Department of Health, 2008a; Health Offender Partnership, 2007).

Actively reaching out to families can reduce levels of distrust incompatible with collaborative working (Eggenberger & Nelms, 2007). It is vital that medium secure services respect parents as expert care partners. (Department of Health, 2008a). It could be argued that because of the demands of public protection, within forensic services, parents have even less influence over the treatment plan than within general psychiatric services. Nevertheless, their views, hopes and concerns about their son or daughter's care and treatment should be sought, listened to, and treated respectfully.

Professionals in general psychiatric services have highlighted that they do not always have skills in dealing with parents (Rose et al., 2004). Psychologists are able to provide training to other disciplines which could address skills deficits such as in conflict resolution, and encourage teams to reflect on the benefits of working with families, and ways in which they can actively collaborate. There should be a lead professional at the regional secure unit where this study took place who will promote these issues for this neglected carer group. The Princess Royal Trust for Carers and the Royal College of Psychiatrists (Partners in Care, 2010) developed a number

of checklists for both psychiatrists and carers, including within forensic services, aimed at facilitating communication (Appendix 23). These could be routinely used by parents and professionals.

For mental health professionals to work effectively with parents of patients within forensic services, it is necessary that they are aware of parents' experiences, which this research study suggests may include feelings of grief, anger and powerlessness. Both the current study and others exploring parents' experience of forensic services (Canning et al., 2009) highlight that parents' trust in mental health systems can be damaged by their previous experience of an unresponsive service. Nevertheless, parents in this study reported a degree of comfort upon their adult-child's admission to the forensic mental health unit, and it is argued that there is no time like the present time for mental health professionals within forensic services to begin to work with parents to develop a collaborative relationship that would benefit all.

Psychologists have appropriate skills and expertise to help parents of forensic service users acknowledge and understand their feelings and experiences, and how these may impact both on their own lives and on their relationships with their son or daughter and professionals involved in their child's care. Granted it is not currently part of a psychologist's role, and there would be resource implications attached- however, active outreach to parents would enable the provision of information, psycho-education, and a safe space where forensic carers could express their thoughts and feelings to professionals if they so choose, and know that they will be heard and respected. Parents have identified feelings of isolation, and support groups

within secure services may provide a system of reciprocal help (McCann, 1993).

It is important that professionals, who are used to working within the forensic mental health system, do not assume that their knowledge is shared by parents. Parents should be provided with information detailing how the forensic mental health system operates, as well as commonly used terminology. This should be followed up with regular opportunities for parents to ask questions of professionals outside of the meetings held regarding their child's progress. Wane et al. (2009) suggest that minimum standards should be established in general mental health services, specifying the level of contact or opportunities to meet the team and plan for the future. These standards could appropriately be applied to forensic services.

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Appendix 1: Search syntax

OVID: PsycINFO (1806 to March week 3, completed on 20th March 2016)

1. exp Family Relations/ or exp Family/ or exp Family Members/ or famil*.mp. (479102)
2. exp CAREGIVERS/ (21793)
3. caregiver*.mp. (42502)
4. exp PARENTS/ (78325)
5. parent*.mp. (240158)
6. exp MOTHERS/ (35387)
7. mother*.mp. (112373)
8. exp FATHERS/ (9356)
9. father*.mp. (42234)
10. exp Adult Offspring/ (3935)
11. adult child*.mp. (5276)
12. relative.mp. (131736)
13. exp SONS/ or son*.mp. (26123)
14. exp DAUGHTERS/ or daughter*.mp. (11933)
15. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (617407)
16. 10 or 11 or 12 or 13 or 14 (171410)
17. 15 and 16 (43292)
18. exp PSYCHIATRIC HOSPITALS/ (7200)
19. exp Mental Health/ (49741)
20. exp Mental Disorders/ (497040)
21. mental* ill*.mp. (46578)
22. exp Hospitalized Patients/ or inpatient.mp. (33201)
23. exp PSYCHIATRIC PATIENTS/ (27692)
24. exp SCHIZOPHRENIA/ (78080)
25. exp PSYCHOSIS/ (99537)
26. exp Bipolar Disorder/ (22061)
27. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 (588082)
28. exp Psychiatric Nurses/ (2958)
29. nurse*.mp. (56201)
30. exp Social Workers/ (10433)
31. exp Health Care Services/ (91790)
32. exp PSYCHIATRISTS/ (10443)
33. exp Clinical Psychologists/ or psychologist*.mp. (84869)
34. exp Mental Health Services/ (35984)
35. exp Mental Health Personnel/ or mental health professional*.mp. (55102)
36. exp CLINICIANS/ or clinician*.mp. (75123)
37. 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 (326683)
38. exp COMMUNICATION BARRIERS/ or exp INTERPERSONAL COMMUNICATION/ or exp COMMUNICATION/ (204322)
39. relationship*.mp. (581838)
40. involvement.mp. or exp INVOLVEMENT/ (90717)
41. exp COLLABORATION/ or collaboration.mp. (32313)
42. interact*.mp. (360595)
43. participat*.mp. (210865)
44. 38 or 39 or 40 or 41 or 42 or 43 (1216628)
45. experience*.mp. (524165)

46. perception*.mp. or exp PERCEPTION/ (474091)
47. perspective*.mp. (226339)
48. exp Attitudes/ or view*.mp. (521452)
49. exp Emotions/ or feel*.mp. (358054)
50. 45 or 46 or 47 or 48 or 49 (1577497)
51. 15 and 16 and 27 and 37 and 44 and 50 (260 records found)

PROQUEST: ASSIA (from 1988 to March week 3, completed on 20th March 2016)

1. (famil?) OR (caregiv?) OR (parent?) (76,454)
2. (adult child?) or (son) or (daughter) (13,737)
3. s1 AND s2 (2,872)
4. (acute inpatient care) OR (mental?) (600)
5. (mental health workers) OR (mental health professionals) (6,853)
6. (relationship?) OR (interaction?) (51,402)
7. (experience?) OR (perspective?) (67,691)
8. (s1 AND s2) AND ((acute inpatient care) OR (mental?)) AND ((mental health workers) OR (mental health professionals)) AND ((relationship?) OR (interaction?)) AND ((experience?) OR (perspective?)) (0)
9. ((famil?) OR (caregiv?) OR (parent?)) AND ((acute inpatient care) OR (mental?)) AND ((mental health workers) OR (mental health professionals)) AND ((relationship?) OR (interaction?)) AND ((experience?) OR (perspective?)) (1)
10. ((famil?) OR (caregiv?) OR (parent?)) AND ((mental health workers) OR (mental health professionals)) AND ((relationship?) OR (interaction?)) AND ((experience?) OR (perspective?)) (67 records found)

EBSCO: CINAHL (from 1981 to March week 3, completed on 20th March 2016)

1. (MH "Family+") (152,680)
2. "famil*" (232,758)
3. (MH "Caregivers") (22,398)
4. (MH "Parents+") (60,926)
5. "parent*" (106,998)
6. (MH "Mothers+") (24,241)
7. "mother" (21,975)
8. (MH "Fathers+") (4,531)
9. "father" (4,700)
10. (MH "Adult Children") (1,899)
11. "adult child*" (2,909)
12. (MH "Young Adult") OR (MH "Adult+") OR "adult offspring" (1,201,858)
13. "relative" (74,520)
14. (MM "Sons") OR "son*" (25,375)
15. (MH "Daughters") OR "daughter*" (3,354)
16. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 (365,973)
17. S11 OR S12 OR S13 OR S14 OR S15 (1,255,902)
18. S16 AND S17 (130,030)
19. (MH "Hospitals, Psychiatric") (5,227)
20. (MH "Mental Health") OR "mental health" (84,514)

21. (MH "Mental Disorders+") (384,549)
22. (MH "Involuntary Commitment") (1,607)
23. (MH "Mental Disorders, Chronic") (1,797)
24. "mental illness" (12,618)
25. (MH "Inpatients") OR "inpatient*" (80,649)
26. (MH "Schizophrenia+") (17,318)
27. (MH "Psychotic Disorders+") OR "psychosis" (83,693)
28. (MH "Schizoaffective Disorder") (115)
29. (MH "Bipolar Disorder+") (7,909)
30. S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 (506,227)
31. (MH "Psychiatric Nursing+") OR "psychiatric nurse" (19,499)
32. (MH "Social Workers") OR "social worker" (9,230)
33. (MH "Multidisciplinary Care Team+") (30,571)
34. (MH "Psychiatrists") OR "psychiatrist" (3,146)
35. (MH "Mental Health Services+") (56,506)
36. (MH "Mental Health Personnel+") OR "mental health professional*" (8,950)
37. "clinician" (12,230)
38. "psychologist" (1,137)
39. S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 (129,773)
40. (MH "Communication+") OR "communication" (215,044)
41. "relationship*" (183,958)
42. "involvement" (35,182)
43. (MH "Collaboration") (26,674)
44. "interact*" (89,209)
45. "participat*" (121,872)
46. S40 OR S41 OR S42 OR S43 OR S44 OR S45 (587,753)
47. "experience*" (221,765)
48. "perception*" (91,384)
49. "perspective*" (76,214)
50. "view*" (67,862)
51. "feel*" (29,582)
52. S47 OR S48 OR S49 OR S50 OR S51 (414,830)
53. S16 AND S17 AND S30 AND S39 AND S46 AND S52 (558 records found)

OVID: Medline (1948 to March week 3, completed on 20th March 2016)

1. exp Family/ (258526)
2. famil*.mp. (934554)
3. exp Caregivers/ (24523)
4. caregiver*.mp. (43800)
5. exp Parents/ (83249)
6. parent*.mp. (352766)
7. exp Mothers/ (31533)
8. mother*.mp (171571)
9. exp Fathers/ (7011)
10. father*.mp. (33747)
11. exp Adult Children/ (890)
12. adult child*.mp. (2311)

13. adult offspring.mp. (1751)
14. relative.mp. (578477)
15. son*.mp. (113512)
16. daughter*.mp. (19664)
17. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 (1392533)
18. 11 or 12 or 13 or 14 or 15 or 16 (708362)
19. 17 and 18 (71009)
20. exp Hospitals, Psychiatric/ (23678)
21. exp Mental Health/ (25382)
22. exp Mental Disorders/ (1026317)
23. *Mentally Ill Persons/ (4230)
24. exp Inpatients/ (15084)
25. exp Schizophrenia/ (91053)
26. exp Psychotic Disorders/ (44726)
27. exp Bipolar Disorder/ (33776)
28. 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 (1066979)
29. exp Psychiatric Nursing/ (15953)
30. nurse*.mp. (277964)
31. exp Social Workers/ (18)
32. exp Patient Care Team/ (58209)
33. psychiatrist*.mp. (18306)
34. exp Mental Health Services/ (80254)
35. mental health professional*.mp. (3540)
36. clinician*.mp. (138382)
37. psychologist*.mp. (10037)
38. 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 (549944)
39. exp Communication/ or communication.mp. (541232)
40. relationship*.mp. (1388732)
41. involvement.mp. (329593)
42. collaboration.mp. or exp Cooperative Behavior/ (68161)
43. interact*.mp. (1097918)
44. participat*.mp. (371581)
45. 39 or 40 or 41 or 42 or 43 or 44 (3397352)
46. experience*.mp. (709265)
47. perception*.mp. (307751)
48. perspective*.mp. (180511)
49. view*.mp. (327310)
50. feel*.mp. (59438)
51. 46 or 47 or 48 or 49 or 50 (1437050)
52. 17 and 18 and 28 and 38 and 45 and 51 (125 records found)

Google Scholar: http://www.scholar.google.co.uk, searched on 12th March 2016

"caregivers" AND "adult child*" AND "mental health" AND "services" AND "experience" (100 records scanned: n.b. this number was a self-imposed limit and doesn't represent the full return, which was 174000. It is common practice for search specialists to typically search the first 50-100 records, therefore I decided on a similar cut-off point)

OpenGrey: http://www.opengrey.eu, searched on 12th March 2016

"caregivers" AND "mental health" (13 records found)

British Library EThOS: http://www.ethos.bl.uk, searched on 12th March 2016

"caregivers" AND "mental health" (15 records founds)

DART Europe E-Theses portal: http://www.dart-europe.eu/basic-search.php, searched on 12th March 2016

“caregivers” AND “adult child*” AND “mental health” AND “services” AND “experience” (19 records found)

Appendix 2: Inclusion and exclusion form

Full reference:

Inclusion criteria	Criterion met?	Comment
Population: Does the population consist of parents/family members supporting an adult child/relative with a mental health condition?	Yes Unclear, discuss No	
Intervention: Is there any communication between parent/family caregivers and mental health professionals providing treatment to their relative with a mental health difficulty?	Yes Unclear, discuss No	What is the nature of this?
Context: Has the family member with mental health needs been admitted to a psychiatric hospital, or other inpatient care facility for mental health treatment?	Yes Unclear, discuss No	
Outcome: Have parent/family caregivers' experiences of contact with mental health professionals been reported? and/or: Have parent/family caregivers' experiences of involvement in care within the inpatient setting, been reported?	Yes Unclear, discuss No	How was this captured? What are parents' perceptions?
Article type: Is the study an original piece of research?	Yes No	
Study design: Did the study employ qualitative methods of data collection and analysis?	Yes No	Stand alone or discrete part of mixed method study?
Language	Include all	
Country of Origin	Include all	
Time Frame	Include all	
Exclusion criteria**:** Data come from family/ parent caregivers of children and adolescents with mental health difficulties; The adult child/relative with mental illness is receiving care in the community, therefore not an inpatient; Studies which *only* use quantitative methods of data collection & analysis, Narrative and Systematic reviews, Letters, Commentaries, Discussion papers, Editorials		

If all questions under heading 'inclusion criteria' are answered with YES, include study.

Appendix 3: Screening of Studies using the Inclusion and Exclusion Criteria

References	Included/excluded?	Reason for exclusion
Albert, R. & Simpson, A. (2015). Double deprivation: a phenomenological study into the experience of being a carer during a mental health crisis. *Journal of Advanced Nursing,* **71** (12), 2753–2762.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Andrew, M., Farhall, J., Ong, B. & Waddell, F. (2009). Perceptions of mental health professionals and family caregivers about their collaborative relationships: A factor analytic study. *Australian Psychologist* **44** (2), 94-104.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Baker-Ericzen, M.J., Jenkins, M.M., Haine-Schlagel, R. (2013). Therapist, Parent, and Youth Perspectives of Treatment Barriers to Family-Focused Community Outpatient Mental Health Services. *Journal of Child and Family Studies* **22** (6), 854-868.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Battams, S. & Roche, A. (2011). Families' Experiences in Wraparound: A Qualitative Study Conceived and Conducted by Families through a Professional-Family Collaboration. *Advances in Mental Health* **10** (1), 62-71.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their

		interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Beaupert, F. & Vernon, A. (2011). 'Odyssey of hope': The role of carers in mental health tribunal processes and systems of mental health care. *Psychiatry, Psychology and Law* **18** (1), 44-68.	Excluded	Intervention and Outcome: Study results did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Bischel, S.L. (2001). Collaboration and Congruence between family member and case manager perceptions in the treatment of individuals with schizophrenia. (Unpublished doctoral dissertation). Cleveland State University.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Blomqvist, M. & Ziegert, K. (2011). 'Family in the waiting room': A Swedish study of nurses conceptions of family participation in acute psychiatric inpatient settings. *International Journal of Mental Health Nursing,* **20**, 185–194.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/parent caregivers looking after a

		mentally ill adult child/relative
Cairns, V.A., Reid, G.S. & Murray, C. (2015). Family members experience of seeking help for first-episode psychosis on behalf of a loved one: a meta-synthesis of qualitative research. *Early Intervention in Psychiatry,* **9,** 185–199.	Excluded	Article type: Systematic review of qualitative studies
Callander, R., Ning, L., Crowley, A., Childs, B., Brisbane, P., Salter, T. (2011). Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia. *International Journal of Mental Health Nursing* **20** (4), 263-273	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Clarke, C. (2006). Relating with professionals. Journal of Psychiatric and Mental Health Nursing, **13** (5), 522-526.	Excluded	Article type: Discussion paper
Clarke, D. & Winsor, J. (2010). Perceptions and Needs of Parents during a Young Adult's First Psychiatric Hospitalization: "We're All on This Little Island and We're Going to Drown Real Soon". *Issues in Mental Health Nursing*, **31**, 242–247.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Cleary, M., Freeman, A. & Walter, G. (2006) Carer participation in mental health service delivery. *International Journal of Mental Health Nursing*, **15**, (3) 189-194.	Excluded	Article type: Discussion paper

Close, N. (1999). Drowning not waving: the parent as co-ordinator of inter-agency support for a child with mental health problems. *Journal of Mental Health* **8** (6), 551-554.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/parent caregivers looking after a mentally ill *adult* child/relative
Cree, L., Brooks, H.L., Berzins, K., Fraser, C., Lovell, K. & Bee, P. (2015). Carers experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC Psychiatry*, 15 (208), 1-11.	**Included**	
Crisanti, A.S. (2000). Experiences with involuntary hospitalization: a qualitative study of mothers of adult children with schizophrenia. *Schizophrenia Research*, **45**, 79–81.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
DeChillo, N., Koren, P.E., Schultze, K.H. (1994). From paternalism to partnership: Family and professional collaboration in children's mental health. *American Journal of Orthopsychiatry*, **64** (4), 564-576.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/parent caregivers looking after a mentally ill *adult* child/relative
Eassom, E., Giacco, D., Dirik A, & Priebe, S. (2014). Implementing family involvement in the treatment of patients with psychosis: a	Excluded	Article type: Systematic review

systematic review of facilitating and hindering factors. *BMJ Open,*1-12.		
Evavold, S.A. (2003). Family Members of the Mentally Ill and their experiences with Mental Health Professionals. (Unpublished doctoral dissertation). Virginia Polytechnic Institute and State University.	**Included**	
Ewertzon, M., Lutzen, K., Svensson, E. & Andershed, B. (2008). Developing the concept of family involvement and the alienation questionnaire in the context of psychiatric care. *International Journal of Mental Health Nursing* **17** (6), 439-449.	Excluded	Study design: Family members' experiences were collected and analysed only quantitative methods
Ewertzon, M., Lutzen, K., Svensson, E. & Andershed, B. (2010). Family members involvement in psychiatric care: experiences of the healthcare professionals approach and feeling of alienation. *Journal of Psychiatric and Mental Health Nursing*, **17**, 422–432.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Fawley-King, K., Haine-Schlagel, R., Trask, E. V., Zhang, J. & Garland, A. F. (2013). Caregiver Participation in Community-Based Mental Health Services for Children Receiving Outpatient Care. *Journal of Behavioral Health Sciences and Research* **40**, (2), 180-190.	Excluded	Population and context: The sample did not elicit the perspectives of the target population which was family/parent caregivers looking after a mentally ill *adult* child/relative. Also, the family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional

		contact they had was community based
Foran Lewis, L. (2015). Balancing Competing Needs: A Meta-Ethnography of Being a Partner to an Individual With a Mood Disorder. *Journal of the American Psychiatric Nurses Association,* **21** (6), 417– 427.	Excluded	Article type: Meta-synthesis of qualitative studies, therefore not primary research
Foster, K. (2011).'I wanted to learn how to heal my heart': Family carer experiences of receiving an emotional support service in the Well Ways programme. *International Journal of Mental Health Nursing,* **20**, 56–62.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Fung, N. (2004). Partners in care and partners in training. *Psychiatric Bulletin* **28** (12), 458-459.	Excluded	Article type: Commentary
Gavois, H., Paulsson,. G. & Fridlund, B. (2006). Mental health professional support in families with a member suffering from severe mental illness: a grounded theory model. *Scandinavian Journal of Caring Sciences*, 20, 102–109.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based

Gerten, A., & Hensley, M. (2014). Transition-Age Children With Mental Illness: Hearing the Voices of Mothers. *Social Work in Health Care*, **53**, 233–249.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Giacco, D., Fiorillo, A., Del Vecchio, V., Kallert, T., Onchev, G., Raboch, J., …Priebe, S. (2012). Caregivers appraisals of patients involuntary hospital treatment: European multicentre study. *The British Journal of Psychiatry*, **201**, 486–491.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Goodwin, V. & Happell, B. (2007) Consumer and carer participation in mental healthcare: The carer's perspective: Part 1- The importance of respect and collaboration. *Issues in Mental Health Nursing* 28, 607-623.	**Included**	
Goodwin, V. & Happell, B. (2007) Consumer and carer participation in mental healthcare: The carer's perspective: Part 2- Barriers to effective and genuine participation. *Issues in Mental Health Nursing* 28, 625-638.	**Included**	
Hatfield, A. B. & Lefley, H. P. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal* **41** (3), 327-338.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Heflinger, C. A., Bickman, L., Northrup, D., Sonnichsen, S. (1997). A Theory-Driven Intervention and Evaluation to Explore Family Caregiver Empowerment. *Journal of Emotional and Behavioral Disorders* **5** (3), 184-191.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Hodgson, O., King, R., Leggatt, M. (2002). Carers of mentally ill people in Queensland: Their perceived relationships with professional mental health service providers: Report on a survey. *Australian e-journal for the advancement of mental health,* **1** (3), 220-234.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods

Horrocks, J., Lyons, C., Hopley, P. (2010). Does strategic involvement of mental health service users and carers in the planning, design and commissioning of mental health services lead to better outcomes? *International Journal of Consumer Studies* **34** (5), 562-569.	Excluded	Intervention and Outcome: Study did not report between family carers and mental health professionals, and did not express the opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Hovish, K., Weaver, T., Islam, Z., Paul, M. & Singh, S. P. (2012). Transition Experiences of Mental Health Service Users, Parents, and Professionals in the United Kingdom: A Qualitative Study. *Psychiatric Rehabilitation Journal*, **35** (3), 251-257.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Howard, P.B. (1994). Lifelong Maternal Caregiving for Children With Schizophrenia. *Archives of Psychiatric Nursing,* **8** (2), 107-114.	Excluded	Intervention and Outcome: Study did not report between family carers and mental health professionals, and did not express the opinions of family caregivers regarding

		their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Ishikura, S., Yamasaki, S. Ando, S., Nishida, A., Tanoue, M., Niimura, J., Asukai, N. & Okazaki, Y. (2015).Association between parents trust in mental health professionals and disengagement from psychiatric service within the first 6 months of initial treatment of schizophrenia. *Early Intervention in Psychiatry,* **9,** 335–338	Excluded	Study design: Family caregivers' experiences were collected and analysed only using quantitative methods
Jakobsen, E.S. & Severinsson, E. (2006). Parents' experiences of collaboration with community healthcare professionals. *Journal of Psychiatry and Mental Health Nursing* 13, 498-505.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Johansson, A., Anderzen-Carlsson, A., Aħlin, A., & Andershed, B. (2010). Mothers Everyday Experiences of Having an Adult Child Who Suffers from Long-Term Mental Illness. *Issues in Mental Health Nursing*, **31**, 692–699.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based

Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2012). Fathers Everyday Experiences of Having an Adult Child who Suffers From Long-Term Mental Illness. *Issues in Mental Health Nursing,* **33** (2), 109–117.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Jones, I., Ahmed, N., Catty, J., McLaren, S., Rose, D., Wykes, T. & Burns, T. (2009). Illness careers and continuity of care in mental health services: A qualitative study of service users and carers. *Social Science & Medicine* **69** (4), 632-639.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Jönsson, P.D., Skärsäter, I., Wijk, H., & Danielson, E. (2011). Experience of living with a family member with bipolar disorder. *International Journal of Mental Health Nursing,* **20**, 29–37.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional

		contact they had was community based
Jubb M. & Shanley E. (2002) Family involvement: the key to opening locked wards and closed minds. *International Journal of Mental Health Nursing* **11** (1), 47-53.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Kaas M.J., Lee S. & Peitzman C. (2003) Barriers to collaboration between mental health professionals and families in the care of persons with serious mental illness. *Issues in Mental Health Nursing* **24**, 741-756.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Kertchok, R. (2014) Building Collaboration in Caring for People with Schizophrenia. *Issues in Mental Health Nursing*, **35** (11), 872-882.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Kertchok, R., Yunibhand, J., & Chaiyawat, W. (2011). Creating a new whole: Helping families of people with schizophrenia. *International Journal of Mental Health Nursing,* **20**, 38–46.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/ parent caregivers looking after a mentally ill adult child/relative
Lakeman R. (2008) Practice standards to improve the quality of family and carer participation in adult mental health care: An overview and evaluation. *International Journal of Mental Health Nursing* **17**, 44-56.	Excluded	Study design: Family members' experiences were collected and

		analysed only using quantitative methods
Lammers J. & Happell B. (2004b) Research involving mental health consumers and carers: a reference group approach. *International Journal of Mental Health Nursing* **13**, 262–266.	Excluded	Article type: Discussion paper
McAuliffe, R., O'Connor, L., & Meagher, D. (2014). Parents experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, **21**, 145–153	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
McCann, T.V., & Lubman, D.I., & Clark, E. (2011). Primary caregivers satisfaction with clinicians response to them as informal carers of young people with first-episode psychosis: a qualitative study. *Journal of Clinical Nursing*, **21**, 224–231.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Mooney, L. R. & Lashewicz, B. (2014). Voices of care for adults with disabilities and/or mental health issues in Western Canada: what do families and agencies need from each other? *Health & Social Care in the Community* **22** (2), 178-186.	Excluded	Population: The sample of participants included family members who provide care for adults with disabilities and/or those with mental health issues. The experiences of the carers who look after adults with

		mental illness were combined with carers of adults with disabilities. Therefore, the perspectives of family caregivers supporting a relative with a mental illness, regarding experiences of contact with mental health professionals isn't clear
Morgan, J., Lowe, J., Lowe, L., & Rathod, S. (2010). Editorial: An international perspective on what carers want- the professional's dilemma. *International Journal of Social Psychiatry*, **56** (3), 211–213.	Excluded	Article type: Opinion Paper
Morin, M.H., & St-Onge, M. (2015). Factors predicting parents' adaptation when supporting their young adult during a first-episode psychosis. *Early Intervention in Psychiatry*, 1-10.	Excluded	Study design: Family caregivers' experiences were collected and analysed only using quantitative methods
Nicholls, E., & Pernice, R. (2009). Perceptions of the Relationship Between Mental Health Professionals and Family Caregivers: Has There Been Any Change? *Issues in Mental Health Nursing*, **30**, 474–481.	Excluded	Context: The family member/relative with mental illness was living in the community at the time they were being supported by a family carer, and the mental health professional contact they had was community based
Nyström, M. & Svensson, H. (2004). Lived experiences of being a father of an adult child with schizophrenia. *Issues in Mental Health Nursing*, **25**, 363–380.	Excluded	Context: The family member/relative with mental illness was living in the community at the time

		they were being supported by a family carer, and the mental health professional contact they had was community based
Perreault, M., Rousseau, M., Provencher, H., Roberts, S., Milton, D. (2012). Predictors of Caregiver Satisfaction with Mental Health Services. *Community Mental Health Journal*, **48** (2), 232-237.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Reid, G. J., Cunningham, C. E., Tobon, J. I., Evans, B. & Stewart, M. (2011). Help seeking for children with mental health problems: parents' efforts and experiences. *Administration and Policy in Mental Health and Mental Health Services Research* **38** (5), 384-397.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/ parent caregivers looking after a mentally ill adult child/relative
Ridley, J., Hunter, S., Rosengard, A. (2010). Partners in care? Views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003. *Health & Social Care in the Community* **18** (5), 474-482.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting

Rooney, R., Wright, B. & O'Neil, K. (2006). Issues faced by carers of people with a mental illness from culturally and linguistically diverse backgrounds: Carers' and practitioners' perceptions. *Australian e-Journal for the Advancement of Mental Health* **5** (2), 1-13.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Schroder, A. & Wilde Larsson, B. (2007). Next of kin's conceptions of the quality of care in the psychiatric setting: A phenomenographic study. *International Journal of Mental Health Nursing* **16** (5), 307-317.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Seeman, M. V. (2013). Spotlight on Sibling Involvement in Schizophrenia Treatment. *Psychiatry* **76** (4), 311-322.	Excluded	Study design: Family caregivers' experiences were collected and

		analysed only using quantitative methods
Simpson, E. & House, A. (2003), User and carer involvement in mental health services: From rhetoric to science. *The British Journal of Psychiatry* **183** (2), 89-91.	Excluded	Article type: Commentary
Simpson, A., Jones, J. Barlow, S. Cox, L. (2014). Adding SUGAR: Service user and carer collaboration in mental health nursing research. *Journal of Psychosocial Nursing and Mental Health Services* **52** (1), 22-30.	Excluded	Article type: Discussion paper
Sjöblom, L.M., Wiberg, L., Pejlert, A. & Asplund, K. (2008). How family members of a person suffering from mental illness experience psychiatric care. *International Journal of Psychiatric Nursing Research,* 13 (3), 1-13.	**Included**	
Solomon, P., Beck, S. & Gordon, B. (1988) Family members' perspectives on psychiatric hospitalization and discharge. *Community Mental Health Journal*, **24**, 108-117.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement in care within the inpatient setting
Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans B., Crosby, M., Killaspy, H., Raine R., Pilling, S. & Johnson, S. (2011). Service user and carer experiences of seeking help for a first episode of psychosis: A UK qualitative study. *BMC Psychiatry* **11**, 157 1-11.	Excluded	Outcome: Study did not express the views or opinions of family caregivers regarding their interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement

		in care within the inpatient setting
Tzeng, H. M. & Yin, C. Y. (2008). Family Involvement in Inpatient Care in Taiwan. *Clinical Nursing Research* **17** (4), 297-311.	Excluded	Study design: Family members' experiences were collected and analysed only using quantitative methods
Van de Bovenkamp, H.M. & Trappenburg, M.J (2009). The relationship between mental health workers and family members. *Patient Education and Counseling*, 80, 120-125.	**Included**	
Van de Bovenkamp, H. M. & Trappenburg, M. J. (2012) Comparative review of family-professional communication: What mental health care can learn from oncology and nursing home care. *International Journal of Mental Health Nursing* **21** (4), 366-385.	Excluded	Article type: comparative review, therefore not a primary research piece
Wallcraft J., Amering M., Freidin J., Davar B., Froggatt D., Jafri H., Javed A., Katontoka S., Raja S., Rataemane S., Steffen S., Tyano S., Underhill C., Wahlberg H., Warner R. & Herrman H. (2011) Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World Psychiatry, **10** (3), 229-36.	Excluded	Article type: Discussion paper
Ward, L., & Gwinner, K. (2014). "It Broke Our Hearts": Understanding Parents Lived Experiences of Their Child's Admission to an Acute Mental Health Care Facility. *Journal of Psychosocial Nursing and Mental Health Services,* **52** (7), 24-29.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/ parent caregivers looking after a mentally ill *adult* child/relative
Watson, A. C., Kelly, B. L. & Vidalon, T. M. (2009). Examining the meaning attached to mental illness and mental health services among justice system-involved youth and their parents. *Qualitative Health Research* **19** (8), 1087-1099.	Excluded	Population: The sample did not elicit the perspectives of the target population which was family/ parent

		caregivers looking after a mentally ill *adult* child/relative
Wilkinson, C. & McAndrew, S. (2008). "I'm not an outsider, I'm his mother!" A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International Journal of Mental Health Nursing*, 17 (6), 392-401.	**Included**	
Winefield, H. R. & Burnett, P. L. (1996). Barriers to an alliance between family and professional caregivers in chronic schizophrenia. *Journal of Mental Health* **5** (3), 223-232.	Excluded	Article type: Discussion paper
Wing Yum Chan, B. & O'Brien, A. (2011). The right of caregivers to access health information of relatives with mental illness. *International Journal of Law and Psychiatry,* **34,** 386–392.	Excluded	Article type: Opinion paper
Wynaden, D. (2006). The Caregiving Experience: How much Do Health Professionals Understand? *Collegian* **13** (3), 6-10.	Excluded	Article type: Discussion paper
Wynaden, D. (2007). The experience of caring for a person with a mental illness: A grounded theory study. *International Journal of Mental Health Nursing,* **16**, 381–389.	Excluded	Intervention and Outcome: Study did not report communication between family carers and mental health professionals, and did not express the opinions of family caregivers regarding interactions with mental health professionals, neither did the study report parent/family caregivers' experiences of involvement

		in care within the inpatient setting
Wynaden, D. & Orb, A. (2005). Impact of patient confidentiality on carers of people who have a mental disorder. *International Journal of Mental Health Nursing* 14, 166-171.	**Included**	

Appendix 4: Quality Assessment Form[1] [2]

Citation:

Screening Questions	
	Comments
Was there a clear statement of the aims of the research? □ yes □ no	Outline the purpose of the study and/or research question.
Is a qualitative methodology appropriate? □ yes □ no	Consider if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
Is it worth continuing? If the answer to both is "yes", it is worth proceeding with the remaining questions.	
Detailed Questions	

[1] Critical Appraisal Skills Programme (CASP). Making sense of evidence. 10 Questions to help you make sense of qualitative research, England: Public Health Resource Unit, 2006.
[2] Critical Review Form - Qualitative Studies (Version 2.0). Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. McMaster University, 2007.

Was the research design appropriate to address the aims of the research? □ yes □ no **Study design** What was the design? □ phenomenology □ grounded theory □ case study □ other	Was the design appropriate for the study question? (i.e. rationale, discussion how they decided which methods to use) Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective.
Was the recruitment strategy appropriate to address the aims of the research? □ yes □ no	Consider (1) if the authors explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study (2) if there are any discussions around recruitment (e.g. why some people chose not to take part)
Were the data collected in a way that addressed the research issue? Method(s) used: □ participant observation □ interviews □ document review □ focus groups □ other _____	Consider (1) if the researcher has discussed saturation, (2) if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide? (3) if the form of data is clear (e.g. tape recordings, video material, notes etc). What was missing and how does that influence your understanding of the research?

Clear & complete description of site: □ yes □ no participants: □ yes □ no	Do the researchers provide adequate information about data collection procedures e.g. gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods Are the participants described in adequate detail? How is the sample applicable to your practice or research question?
Ethics Have ethical issues been taken into consideration? □ yes □ no	Consider (1) if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained (2) if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) (3) if approval has been sought from the ethics
Has the relationship between researcher and participants been adequately considered? □ yes □ no □ not addressed Identification of assumptions and biases of researcher: □ yes □ no	Consider whether it is clear: (1) if the researcher critically examined their own role, potential bias and influence during: – formulation of research questions – data collection, including sample recruitment and choice of location (2) how the researcher responded to events during the study and whether they considered the implications of any changes in the research design
Was the data sufficiently rigorous? Data analyses were inductive? □ yes □ no □ not addressed	Describe method(s) of data analysis. Were the methods appropriate? e.g. if thematic analysis is used is it clear how the categories/themes were derived from the data? Consider whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process. Consider if sufficient data are presented to support the findings (authors include in the paper the quotes) and to what extent contradictory data are taken into account

Findings were consistent with & reflective of data? □ yes □ no Decision trail developed? □ yes □ no □ not addressed Process of analyzing the data was described adequately? □ yes □ no □ not addressed Did a meaningful picture of the phenomenon under study emerge? □ yes □ no	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes. How were concepts under study clarified & refined, and relationships made clear? Describe any conceptual frameworks that emerged. Consider: (1) if the findings are explicit (2) if there is adequate discussion of the evidence both for and against the researcher's arguments (2) if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.) (3) if the findings are discussed in relation to the original research questions
Is there a clear statement of the findings? □ yes □ no	Summary of results presented at the beginning of the results section.

How valuable is the research? Conclusions were appropriate given the study findings? □ yes □ no The findings contributed to theory development & future practice/ research? □ yes □ no	Consider: (1) if the researcher discusses the contribution the study makes to existing knowledge or understanding (2) if they identify new areas where research is necessary (3) if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Throughout the form, “no” means the authors explicitly state reasons for not doing it; “not addressed” should be ticked if there is no mention of the issue.

Appendix 5: Data Extraction Form

NICE data extraction form (British Psychological Society & Gaskell 2007)
Eligibility: Does the evidence fit within the scope of the review? Type of study Participants Study aims • *Are the aims and purpose of the study clearly stated?* Key findings Evaluative summary: Draw together brief comments on the study as a whole and its strengths and weaknesses. Is further work required? What are its implications for policy, practice and theory, if any? Ethical standards: Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately? Has confidentiality been maintained? Area and care setting: • *What is the geographical and care setting for the study?* • *What is the rationale and appropriateness for this choice?* • *Is there sufficient detail about the setting?* • *Over what period did the data collection take place?* Sample: • *Inclusion and exclusion criteria: Who was included in the study? Who was excluded from the study?* • *Selection: How was the sample selected? Were there any factors that influenced how the sample was selected (e.g. access, timescale issues)?* • *Size: What is the size of the sample and groups comprising the study?* Data collection: • *Methods: What data collection methods were used? Was the data collection adequately described and rigorously conducted?* • *Role of researcher: What is the role of the researcher within the setting? Are there any potential conflicts of interest?*

Data analysis:

- *How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis (e.g. use of original data, iterative analysis, efforts to establish validity and reliability)? Is the study set in context in terms of findings and relevant theory?*
- *Researchers' potential bias: Are the researchers' own position, assumptions and possible biases outlined? Indicate how they could affect the study in terms of analysis and interpretation of the data*
- *Reflexivity: Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?*

Findings:

- *Themes*
- *Conclusions*
- *Opinions: What this person argues*

Policy and practice:

- *Generalisability: To what extent are the study findings generalisable? What is the country of study? How applicable are the study findings to the system in the UK? Are the conclusions justified?*
- *Implications for policy*
- *Implications for practice*

Appendix 6: Guidance for meta-ethnography (Noblit & Hare, 1988)

This approach consists of a series of seven phases that overlap and repeat as the meta-synthesis progresses:

(a) Getting started and deciding on a phenomenon of study.
(b) Deciding what qualitative studies are relevant to the initial interest.
(c) Reading the qualitative studies.
(d) Determining how the studies are related to each other. In this phase, the synthesiser makes a list of the key metaphors in each study and their relations to each other. The term metaphor refers to themes, concepts, or phrases. Three different assumptions can be made about the relationships between the studies to be synthesised. These key assumptions are "(1) the accounts are directly comparable as 'reciprocal' translations; (2) the accounts stand in relative opposition to each other and are essentially 'refutational'; or (3) the studies taken together present a 'line of argument' rather than a reciprocal or refutational translation." (Noblit & Hare, 1988, p.36)
(e) Translating the studies into one another.
(f) Synthesising translations. This involves creating a whole as something more than individual parts imply. The translations as a group are one level of a meta-synthesis. Next, the translations can be compared to decide if the same metaphors/themes or concepts can be encompassed into those of others. This is a second level of synthesis.
(g) Expressing the synthesis through the written word, plays, art, videos, or music.

Appendix 7: Ethical approval

Business Services Organisation
Providing Support to Health and Social Care

HSC REC 2

Office for Research Ethics Committees Northern Ireland (ORECNI)

Customer Care & Performance Directorate
Office Suite 3
Lisburn Square House
Haslem's Lane
Lisburn
Co. Antrim BT28 1TW
Tel: + 44 (0) 28 9260 3107
Fax: + 44 (0) 28 9260 3619
www.orecni.hscni.net

18 April 2012

Professor Kevin Browne
Director of the Professional Doctorate Programme in Forensic Psychology
University of Nottingham
Institute of Work, Health & Organisations
University of Nottingham, International House
Jubilee Campus, Nottingham
NG8 1BB

Dear Professor Browne

Study title: **Parental perspectives: Being a parent of a son or daughter in adult medium secure care**

REC reference: **12/NI/0028**

Thank you for your letter of 04 April 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a sub-committee of the REC at a meeting held on 18 April 2012. A list of the sub-committee members is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

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

Conditions of the favourable opinion

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

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

Approved documents

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

Document	*Version*	*Date*
Covering Letter	Signed Gemma Finlay	14 February 2012
Evidence of insurance or indemnity	Henderson Corporate	26 July 2011
Interview Schedules/Topic Guides	1.0	14 February 2012
Investigator CV	Prof Kevin Browne (CI), Dr John Ferguson, Jason Davies, Gemma Finlay	
Letter from Sponsor	University of Nottingham	15 February 2012
Letter of invitation to participant	2.0 (Patient Cover Letter)	27 March 2012
Letter of invitation to participant	2.0 (Parent Cover Letter)	27 March 2012
Other: BHSCT Honorary Contract	Miss Gemma Finlay	07 October 2011
Other: Parent Follow up Letter	1.0	27 March 2012
Participant Consent Form	2.0 (Patient)	27 March 2012
Participant Consent Form	2.0 (Parent)	27 March 2012
Participant Information Sheet	2.0 (Clinical Team)	27 March 2012
Participant Information Sheet	2.0 (Patient)	27 March 2012
Participant Information Sheet	2.0 (Parent)	27 March 2012
Protocol	2.0	27 March 2012
REC application	3.4	14 February 2012
Response to Request for Further Information	Cover letter addressing response to provisional opinion	04 April 2012

Statement of compliance

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

After ethical review

Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators

- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NI/0028	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

p.p. Katrina Greer

Dr Donna Fitzsimons
Chair of the Meeting

Email: katrina.greer@hscni.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to:

Mr Paul Cartledge
Head of Research Grants & Contracts
Research Innovation Services
King's Meadow Campus
Lenton lane
Nottingham
NG7 2NR

Ms Alison Murphy
Research Governance Office
Belfast HSC Trust
2nd Floor, King Edward Building
Royal Victoria Hospital
Grosvenor Road
BELFAST
BT12 6BA

Miss Gemma Finlay
62 Drumreagh Road
Ballygowan
Newtownards
BT23 6LA

Appendix 8: Participant Information Sheet- Clinical Team

Belfast Health and Social Care Trust

The University of Nottingham

Participant Information Sheet- Clinical Team

(Version 2.0 Date 27.03.12)

Parental perspectives: Being a parent of a son or daughter in adult medium secure care.

Background & Purpose

Little is currently known about the experiences of parents who have a son or daughter in adult medium secure forensic mental health care. Research with parents whose adult children have schizophrenia suggests that caring is a life-long effort embedded in the struggle to remain lovingly connected to the child while coming to terms with loss, and sacrificing personal goals to support the child consumes parents' resources and challenges their sense of identity. The purpose of this study is to extend existing knowledge and specifically to: (a) understand the experience of parents who have a mentally ill son or daughter who is in secure forensic mental health care (b) consider the parent's experience of professional care for their family member (c) explore the experience of care-giving and the relationship between the parent and child from the parent perspective. It is anticipated that exploration of family member's thoughts and feelings in this study will increase professional knowledge of what relatives face and facilitate communication and understanding between members of the clinical team, the patient with mental health problems and their families.

Procedure

The research will follow a sequence as outlined below

Clinical team identifies patients who meet study inclusion criteria. Cases are discussed with patient's Consultant who approves which patients from this group can receive information about the study.

Eligible patients are given a cover letter and information sheet by the clinical team. Patient asked if they are willing for a member of the patient's care team to go through this information with them at a suitable time and answer any questions.

After a 'cooling off' period of 24-48 hours following the discussion between a member of the clinical team and the patient, the patient's decision about permission to contact their parents is followed up by this individual.

The researcher Gemma Finlay will make weekly contact with Consultant Psychiatrists for each of the clinical teams at the unit to monitor the number of patients approached who have spent time with a member of their care team to gain an understanding of the research project.

Signed consent forms will be handed over to Gemma Finlay which will enable her to access the patient's medical file to find out basic information including reasons for admission and length of stay. The returned consent forms will also contain the names and addresses of the parent(s) whom the patient has nominated for inclusion into the study.

Consultant Psychiatrist for the patient signs a cover letter to the parents introducing Gemma Finlay and this along with a participant information sheet which outlines the study is sent to parents of patients who approved contact. These forms will be posted by Gemma Finlay after a period of 7 days.

Parents who are considering taking part in the study contact Gemma Finlay. Participant's rights and informed consent are discussed.

Parents who meet inclusion criteria will be interviewed once for approximately 60-90 minutes by Gemma Finlay at a private office or the participant's home if requested.

Who is eligible to take part in the study?

Patients who are approached to invite their parents to take part in an interview will meet the following criteria: (a) a diagnosis of psychosis – schizophrenia, schizoaffective or other psychotic disorder for a minimum of six months established by the Consultant Psychiatrist (b) aged 18 years or older (c) stable with regard to their mental state, i.e., a patient on remission or maintenance treatment (d) to have resided in [redacted] medium secure unit for at least six months (e) have capacity to provide informed consent (f) is in regular contact with a parent or guardian

Parents of patients must meet the following criteria:(a) have the capacity to express themselves and be willing to communicate their experiences to the researcher (b) have regular contact with their son/daughter at least once per month (c) be able to speak and read English

What part does the Clinical Team and Consultant Psychiatrist have in this study?

We need the help of patient Consultants and clinical teams to identify which individuals may be approached. Secondly, the standardized introductory letter to parents will need to be signed by the patient's Consultant.

Will the Clinical Team and Consultant Psychiatrist know which parents of patients end up taking part in the study?

None of the patient's care team will be aware of individual parents who agree to take part, however the general findings of the study will be made available for clinic staff to use as they see most appropriate.

What will happen to the results of the research study?

The results of the study will be used in a Doctorate thesis and in reports to health services. The material will be presented at professional conferences and in academic journals. Anonymity and confidentiality will still be in place in all cases. Findings from this study will contribute to developing a better understanding of how forensic mental health services can support parents of children with mental illness in a forensic in-patient unit.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Gemma Finlay.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the Research Ethics Committee for Northern Ireland. Research Governance approval has been granted from the Belfast Health and Social Care Trust.

Further information and contact details

If you have any questions about any aspect of the study please do not hesitate to contact members of the research team listed below who will be happy to discuss the research process in detail.

Researcher: Gemma Finlay

Forensic Psychologist in Training

Work Mobile: [redacted]

E-mail: [redacted]

Academic Supervisor: Dr Jason Davies

Consultant Forensic and Clinical Psychologist

Phone: [redacted]

E-mail: [redacted]

Academic Supervisor: Dr John Ferguson

Consultant Clinical Psychologist

Phone: [redacted]

E-mail: [redacted]

Academic Supervisor: Kevin Browne

Prof. Forensic Psychology & Child Health

Phone: [redacted]

Email: [redacted]

<u>Thank you for assisting with this research</u>

Appendix 9: Participant Information Sheet- Patient

Belfast Health and Social Care Trust

The University of Nottingham

Participant Information Sheet- Patient

(Version 2.0 Date 27.03.12)

Study Title: Parental perspectives: Being a parent of a son or daughter in adult medium secure care.

Names of Researchers: Gemma Finlay, Dr Jason Davies, Dr John Ferguson, Prof. Kevin Browne

We would like to seek your permission to contact your parents/ the persons who brought you up to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully. *Thank you for taking the time to read this*.

What is the purpose of the study?

The focus of the research is to learn about what it is like for parents who have a son/daughter in a medium secure forensic unit ([redacted]) and explore parents' experiences of contact with professionals who look after their family member. This study is an original piece of work and it is important that parents have the opportunity to air their views. Understanding and listening to parents in this situation, will allow forensic mental health staff to think about and possibly improve the way they currently work with families and the individual family member with mental health needs. This project is also part of the requirements for Nottingham University's Doctorate in Forensic Psychology.

Why have I been asked?

You have been approached because your clinical team has indicated that you have contact with your parent/ guardian on a regular basis whilst at [redacted] Clinic. In order to ensure that confidentiality rules are kept we are asking your permission to contact your parent(s). A member of the clinical team will have given you this information sheet and cover letter which gives an outline of the research. If you agree that this person can meet with you to discuss this information and answer any questions you have, then the member of staff will arrange to do this at a time that is best for you. After you have had the opportunity to discuss the project with a member of the clinical team this person will follow up your decision within 2 days.

Do I have to take part?

It is up to you to decide whether or not to allow Gemma Finlay to send your parents similar study information to what you have been given. If you give permission for your parents to be contacted you will be asked to sign a consent form to record this decision. Gemma will also seek permission to look at your medical file to find out some basic information about you such as the reasons for admission and length of stay. Any information gathered from your file will be nameless (anonymised) to protect your confidentiality. You WILL NOT be interviewed as this study focuses on parents' experiences.

What will happen next?

Your Consultant Psychiatrist will sign a cover letter to be sent to your parents introducing Gemma Finlay who is organising the parent interviews. This is because Gemma Finlay does not know your parents, however your parents will already be familiar with your Consultant, and by them putting their signature on the cover letter it lets parents know that the clinical

team looking after you are aware that this study is taking place, and staff have agreed to help Gemma Finlay get in touch with parents whose son or daughter is in [redacted] Clinic. Parents who have read the cover letter and information sheet and are considering taking part in the study will contact Gemma Finlay by telephone. The researcher will explain to parents their participant rights, discuss informed consent and arrange a time that is convenient for them to be interviewed. Interviews will take place in a private office at [redacted] Clinic which is located a few minutes' walk from [redacted] Clinic in the grounds of [redacted]. If this is not possible for your parents then it may be possible for the interview to take place in the family home. The interview is expected to last approximately 60-90 minutes. All interviews will be conducted by Gemma Finlay. During the interview parents will be asked about their experiences of things including what it is like being a parent of a son/daughter in a secure unit, as well as parent experiences of mental health services.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks or harm that may result from consenting to your parents being contacted about the study. Similarly, there are no foreseeable risks or harm that may result from your parents participating in the interview. If there are questions which your parents find are uncomfortable, they will be assured that they do not have to answer them and if they want to break or end the interview they can at any time. After the interview, the researcher will provide parents with written information on services which are available locally which provide support to carers who have a family member with mental health difficulties.

What are the possible benefits of taking part?

There will be no immediate and direct benefit to your parents or to you, but your parent's participation is likely to help us find out more about the personal experience of parenting a son/daughter in a medium secure unit and we hope that this information will help [redacted] Clinic meet parents' needs better in the future. Your treatment will not be affected whether or not you allow Gemma Finlay to contact your parents. Also, your treatment will not be affected in any way whether or not your parents take part.

What will happen if I don't want to carry on with the study?

Once you give permission for your parents to be contacted we will ask them to consent to participate. **You will not be asked to do anything else as part of the study**. If you give your permission for your parent(s) to be contacted they will not be sent any information for at least 7 days. During this time, if you change your mind about your parents being contacted please let Gemma know. This can be done by speaking to one of your medical team, who will then contact Gemma on your behalf. She will then remove your parents from the list of people to be approached.

What will happen to the results of the research study?

Once the study has been written up for the Doctorate thesis, the researcher will send parents a summary of the study findings (if they want this). The researcher intends to share the information with mental health professionals working at [redacted] Clinic and discuss how parent experiences can be taken into account by the service.

Will information about me and my parents be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, some parts of your medical records and the data collected from your parents for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Although what your parent(s) says in the interview is confidential, should they disclose anything to the interviewer which suggests that either you or themselves are at risk of harm,

then the interviewer is obliged to breach confidentiality and inform someone (this is likely to be a Social Worker or Consultant Psychiatrist within a patient's care team at [redacted] Clinic).

All information which is collected about you/from your parents during the course of the research will be stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your parent's personal data (address, telephone number) will be kept for 3-6 months after the end of the study, so that we are able to contact them about the findings of the study (unless they advise us that they do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your/your parent's confidentiality, only members of the research team will have access to your/your parent's personal data. Information about your parent's experiences will be typed up, but any mention of you or your family member's names will be changed to protect everyone's identity.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being self-funded by the researcher Gemma Finlay.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Office for Research Ethics Committee Northern Ireland.

Further information and contact details

If you have any questions please do not hesitate to contact Dr. John Ferguson, your Consultant Psychiatrist or members of your clinical team in the usual way. Gemma Finlay can also provide further study information if requested. She can be contacted via your care team.

Thank you for reading this information sheet, and if it is possible, participating in the study.

Appendix 10: Participant Information Sheet- Parent





Participant Information Sheet- Parent

(Version 2.0 Date 27.03.12)

Study Title: Parental perspectives: Being a parent of a son or daughter in adult medium secure care.

Names of Researchers: Gemma Finlay, Dr. Jason Davies, Dr. John Ferguson, Prof. Kevin Browne

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Health professionals would like greater involvement and support for families of people with mental illness. However, to date there have been no studies which have explored the personal experience of parents of children with mental illness in a forensic in-patient unit. This research project is concerned with (a) developing an understanding of the experience of parents who have a mentally ill son/daughter who is in secure forensic mental health care (b) exploring the parent's experience of professional care for their family member (c) understanding the experience of care-giving and the relationship between the parent and child from the parent perspective.

Why have I been invited?

You have been invited to participate in this study having been identified as a parent with a son or daughter with mental illness receiving professional care in a secure adult mental health setting. This study was discussed with your child at their most recent case conference and permission was sought from them to send you information outlining the research study. We believe families of persons who receive psychiatric services have important and unique experiences to share, which can provide valuable feedback regarding the support being offered to parents in this context.

Do I have to take part?

It is up to you to decide whether or not to take part and the staff at the clinic WILL NOT know whether or not you take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights and will not affect your relationship with the clinic. Whether or not you take part WILL NOT affect your son or daughter's care and treatment.

What will happen to me if I take part?

After reading this information sheet, please contact the lead researcher Gemma Finlay if you would like to participate in an interview. Contact details are at the end of this information sheet. If you agree, the researcher will check some details with you and discuss the process more fully. During this phone call, Gemma will seek your verbal consent to participate and arrange a time that is convenient for you to be interviewed. Interviews will take place in a private office at [redacted] Clinic which is located a few minutes walk from [redacted] Clinic in

the grounds of [redacted]. If this is not possible for you, then it may be possible for the interview to take place in your home. The interview is expected to last approximately 60-90 minutes. All interviews will be conducted by Gemma Finlay. During the interview you will be asked about your views and experiences of a range of things including the events surrounding the diagnosis of your child's illness and your experiences of personal involvement in care, as well as your experiences of mental health professionals. All interviews will be audio recorded and then transcribed. The audio tapes will be stored in a locked secure place at all times and the computer data will be protected. Your responses will be treated with full confidentiality and anyone who takes part in the research will be identified only by code numbers or false names.

Expenses and payments

You will not be paid to participate in the study. However, the researcher will arrange the interview at a time and date to suit you, so that you do not incur any unnecessary inconvenience by participation.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks or harm that may result from the interview. If there are questions which you find are uncomfortable, you do not have to answer them. You can request to break or end the interview at any time. After the interview, the researcher will provide you with written information on services which are available locally which provide support. This list is also at the end of this information sheet.

What are the possible benefits of taking part?

We cannot promise the study will benefit you, although you may find it helpful to tell your account in your own words. The information that is learned from this study may help improve mental health professionals' understanding of what relatives of persons with mental illness face, and the findings may provide new suggestions about working with parents in this situation.

What happens when the research study stops?

Once the study has been written up, the researcher will send you a summary of the study findings (if you want this). The researcher intends to share the study findings with mental health professionals working at [redacted] Clinic and discuss how parents' experiences can be taken into account by the service. You will not be able to be identified in the communication of findings.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting HSC Complaints. Details can be obtained from [redacted] Clinic.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. Data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

If you have asked for a summary of the findings, your address details will be kept for 6 months after the end of the study so that we can send you the summary. These details will be kept separately to the information you have given and will not be able to be linked with your information in any way. As with all research data, your anonymised data will be kept securely for 7 years, after which it will be disposed of securely. During this time all precautions will be taken to maintain your confidentiality.

Although what you say in the interview is confidential, should you disclose anything to the interviewer which suggests that either your family member or yourself, is at risk of harm then the interviewer is obliged to breach confidentiality and inform someone (this is likely to be a social worker or patient's clinician from [redacted] Clinic). The researcher will do her best to discuss this with you first.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. However, because of the way the data is anonymised it will not be possible to withdraw your data after the interview is concluded.

What will happen to the results of the research study?

The results of the study will be used in a Doctorate thesis and in reports to health services. The material will be presented at professional conferences and in academic journals. Anonymity and confidentiality will still be in place in all cases. Findings from this study may contribute to developing a better understanding of how forensic mental health services can work with parents.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Gemma Finlay.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Committee for Northern Ireland.

Further information and contact details

Should you have any questions after reading this information or similarly, if you would like any further information, please do not hesitate to contact members of the research team:

Researcher: Gemma Finlay
Forensic Psychologist in Training
Work Mobile: [redacted]
E-mail: [redacted]

Academic Supervisor: Dr Jason Davies
Consultant Forensic and Clinical Psychologist
Phone: [redacted]
E-mail: [redacted]

Academic Supervisor: Dr John Ferguson
Consultant Clinical Psychologist
Phone: [redacted]
E-mail: [redacted]

Academic Supervisor: Kevin Browne
Prof. Forensic Psychology & Child Health
Phone: [redacted]
E-mail: [redacted]

Thank you for reading this information sheet, and if it is possible, participating in the study.

More information on locally available services and organisations that offer help and support to people caring for persons with mental health problems.

- **Carers Northern Ireland** is the regional office of Carers UK. It is a membership organisation run by carers, for carers across the whole of Northern Ireland. There are approximately 250,000 carers in Northern Ireland. To find out more go to www.carersni.org

- **CAUSE** is a local charity providing peer-led emotional and practical support to carers and families of people with serious mental illness. Services include support groups, a helpline, carer advocacy, educational programmes and representation of carers' views. Email: info@cause.org.uk

- **Action Mental Health** (AMH) aims to enhance the quality of life and employability of people with mental health needs or a learning disability. Telephone: 02890 403726

- **MensSana**, meaning 'healthy mind' provides an advice and information service for parents and professionals concerned about the mental health of a young person aged 16-25. Tel: 028 3839 2314 or Email: info@menssanaproject.org.uk

- **Northern Ireland Association for Mental Health** (NIAMH) provides local support and offers a range of services including housing schemes, home support, advocacy, information, public education and research. Email: info@niamhwellbeing.org or telephone: 02890 328474

- **Parenting NI** provides a free confidential helpline and appointment service for family members experiencing relationship, behavioural or emotional problems in their child. They can facilitate referrals to other specialist help. The service operates from 4 branches: Belfast, Derry, Dungannon and Ballymena, and is operated by volunteers trained to recognised standards, to provide support and guidance to parents of children of any age. Call the parents helpline on 0808 8010 722

- **Rethink** works to help everyone affected by severe mental illness recover a better quality of life. They provide hope and empowerment through effective services and support and to all those who need assistance, and campaign for change through greater awareness and understanding. For further information on Rethink telephone: 0845 456 0455 or Email: info@rethink.org

Appendix 11: Invitation letter- Patient copy

Belfast Health and Social Care Trust

The University of Nottingham

Patient Cover Letter
(Version 2.0 Date 27.03.12)

Dear……,

My name is Gemma Finlay and I work as a trainee Forensic Psychologist under the supervision of Dr. John Ferguson, Psychologist at [redacted] Clinic. I am carrying out research as part of a doctorate undertaken at the University of Nottingham, which might help clinic staff understand and do more to help parents who have a son or daughter in a medium secure hospital. In the research I will talk to parents and ask them a number of questions about their experiences. However, before I do this, I want to ask your permission to send them some information about the study.

You do not have to decide today whether or not you agree to your parents being contacted about this research. Before you decide, you can talk to your Consultant who is aware of this study, other members of the clinical team, or you may ask myself or John Ferguson any questions that you may have. We will take time to explain things to you and your decision can be given within a couple of days. If you agree, then you will be asked to sign a consent form. **The standard of care you receive will not change whether or not you decide that your parents can be notified about this study.**

The next thing I will do is ask your mother and/ or father for their agreement as well. Both you and your parent(s) have to agree independently before I can begin the research. You can choose which of your parents receive the study information. It can be either your mother or your father, or both if you are in agreement. **You WILL NOT be interviewed yourself** although I will ask your permission to look at your medical file and this decision will also be recorded on the consent form which you will be asked to sign. If during the interview your mother/father does not wish to answer a question, they may say so and I will move on to the next question. The interview will take place in either a private office in [redacted] grounds or your parent's home and no one else but myself will be present. Altogether I am asking for up to 90 minutes of your parent's time.

There will be no immediate and direct benefit to your parents or to you, but your parent's participation is likely to help us find out more about the personal experience of parenting a son/daughter in a medium secure unit and we hope that this information will help [redacted] clinic meet parents' needs better in the future. **Your treatment will not be affected in any way whether or not your parents take part.**

We will not be sharing personal information about you or your parents outside of the research team. The information that we collect from this research project will be kept confidential. Information about your parents' experiences will be typed up but within these accounts any mention of you or your family members will be changed to protect everyone's identity.

At the end of the study, I will be sharing what I have learnt with parents and with the clinical teams. I will also publish the results in order that other interested people may learn from this research. You or your parents will not be able to be identified in the study findings. This research has been reviewed and approved by ethical committees to make sure that anyone involved in research is protected from harm. Attached is a '*participant information sheet*' which provides more detail about the research study.

Thank you for taking the time to read this and consider my request.

Yours Sincerely,

Gemma Finlay

Appendix 12: Invitation letter- Parent copy

Belfast Health and Social Care Trust

The University of Nottingham

Parent Cover Letter
(Version 2.0 Date 27.03.12)

Dear ……,

Re: Research Project **'Parental perspectives: Being a parent of a son or daughter in adult medium secure care'**

My name is Gemma Finlay and I work as a trainee Forensic Psychologist under the supervision of Dr John Ferguson, Psychologist at [redacted] Medium Secure Unit. I am conducting research as part of a doctorate programme which might help clinic staff understand and do more to help parents who have a son or daughter in a forensic mental health setting.

This doctoral research is being organised by the University of Nottingham and is being overseen by others in the research team namely; Dr Jason Davies, Professor Kevin Browne and Dr John Ferguson. Prior to contacting you about this study ethical and research governance approval for the project was obtained from the Northern Ireland Research Ethics Committee and Belfast Health and Social Care Trust. Also, permission to contact you about participation in an interview as part of the study has been given by (insert name of son/daughter).

The aims of the research project are to (a) develop an understanding of the experience of parents who have a mentally ill son/daughter who is in secure forensic mental health care (b) explore the parent's experience of professional care for their family member (c) understand the experience of care-giving and the relationship between the parent and child from the parent perspective. Presently, little is known about the experiences of parents who have a son or daughter in adult medium secure forensic mental health care. This study is an original piece of work and it is important that parents have the opportunity to air their views. Understanding and listening to parents in this situation will allow forensic mental health staff to think about, and possibly improve the way they currently work with families and the individual family member with mental health needs.

Identification of parents has been possible via patients who are being cared for by the clinical team in [redacted] and I am writing to you to kindly ask if you would be interested in taking part in an interview with myself, which will last approximately 60-90 minutes. The interview will provide you with an opportunity to tell your story of what it is like to have a mentally ill family member and discuss involvement in their care. **Only insert the following sentence if the patient has given permission for both parents to receive study information.** You can choose whether you are interviewed individually or together with Mr/Mrs Surname [insert other parent name] as your son/daughter [delete as appropriate before sending] has also nominated them.

After reading the accompanying information sheet which describes the project in further detail, if you would like to be considered for participation in this study please

contact me; these details can be found at the end of the participant information sheet which accompanies this letter. I will arrange a suitable time and date for interview and answer any questions that you might have. Please note, *although the clinic is hosting this research, the clinical team will not know which parents have taken part and will only be given the overall findings of the study*.

Thank you for considering this request.

Yours sincerely,

Gemma Finlay Counter Signed by Consultant Psychiatrist

Appendix 13: Follow up letter- Parent

Belfast Health and Social Care Trust

The University of Nottingham

Parent Follow up Letter

(Version 1.0 Date 27.03.12)

Dear [……],

Re: Research Project **'Parental perspectives: Being a parent of a son or daughter in adult medium secure care'.**

I am following up on my earlier request to invite you to participate in a study which explores parents' experiences of care giving for an adult son/daughter in medium secure care. The study also aims to understand parents' experiences of contact with professionals who look after their family member.

This study is being undertaken as part of the requirements for Nottingham University's Doctorate in Forensic Psychology. It is an original piece of work and it is hoped that this study will emphasise the voices of parents and enhance healthcare professionals understanding and provide valuable feedback regarding the support being offered to parents in this context.

If you would like to participate in an interview, which is expected to last approximately 60-90 minutes, please contact myself, Gemma Finlay by telephone on [redacted]. I will call you back and discuss the process fully.

During this phone call, I will seek your verbal consent to participate and arrange a time that is convenient for you to meet with me in person. Interviews will take place in a private office at [redacted] Clinic which is located a few minutes walk from [redacted] Clinic in the grounds of [redacted]. If this is not possible for you, then it may be possible for the interview to take place in your home. All interviews will be conducted by myself.

During the interview you will be asked about your views and experiences of a range of things including the events surrounding the diagnosis of your child's illness and your experiences of personal involvement in care as well as your experiences of involvement with mental health professionals. The interview will be audio-recorded.

After the interview, you will have an opportunity to ask any questions and raise any concerns you may have. I will be able to advise you of who you can talk to if you need further support, and will give you an information sheet with details of sources of support.

Once the study has been written up, I will send you a summary of the overall study findings (if you want this). It is my intention to share the study findings with mental health professionals working at [redacted] Clinic and discuss how parents' experiences can be taken into account by the service. Please note, *although the clinic is hosting this research, the clinical team will not know which parents have taken part and will only be given the overall findings of the study*. **Thank you for taking the time to read this and if it is possible participating in the research.**

Yours sincerely, Gemma Finlay Counter Signature of Consultant Psychiatrist

Appendix 14: Consent form- Patient

Belfast Health and Social Care Trust

The University of Nottingham

CONSENT FORM - Patient
(Version 2.0 Date 27.03.12)

Title of Study: Parental perspectives: Being a parent of a son or daughter in adult medium secure care

REC ref: 12/NI/0028

Name of Researcher: Gemma Finlay

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated ..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

4. I understand that there are limits to confidentiality. If my parent(s) disclose any information during interview which puts myself or themselves at risk, this will be reported to the appropriate persons. ☐

5. I agree that my parent(s) can be contacted about the study ☐

   Name of parent/guardian _____

   Address _____

   Telephone number _____

Name of parent/guardian _____

Address _____

Telephone number _____

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

* 3 copies: 1 for participant, 1 for the project notes and 1 for the participant's medical notes.

Appendix 15: Consent form- Parent

Belfast Health and Social Care Trust

The University of Nottingham

CONSENT FORM - Parent
(Version 2.0 Date 27.03.12)

Title of Study: **Parental perspectives: Being a parent of a son or daughter in adult medium secure care**

REC ref: 12/NI/0028

Name of Researcher: Gemma Finlay

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated ..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that there are limits to confidentiality. If I disclose any information during interview which puts my family member in [redacted] Clinic, or myself at risk, this will be reported to the appropriate persons. ☐
5. I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐
6. I agree to take part in the above study ☐
7. Optional: I would like to receive a copy of the results of the study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

* 3 copies: 1 for participant, 1 for the project notes and 1 for the participant's medical notes.

Appendix 16: Interview Schedule

(Final Version 1.0 Date 14.02.12)

Introduction

- Thank parent(s) for meeting with me.
- Read the following orienting statement to parent(s) to explain purpose of interview and format.

'There is a lack of knowledge about the experience of parents whose children are living in a medium secure setting. I am interested in gaining an understanding into what parenting has been like for you and how you have made sense of your experiences. I believe that each of you has had a unique journey so far and it is important that the family caregiver's perspective is presented for health professionals to respond to and learn from. The information that you give will be tape-recorded to allow your responses to be represented accurately. Your responses will be confidential and you will not be able to be identified from the summary results. The interview is expected to take 60-90 minutes and you are under no obligation to discuss anything that you are not comfortable with.'

- Ask parent(s) –Do you have any questions before we begin?
- Go through informed consent with parent(s)
- Turn on recording equipment.

1. Please tell me about a recent time you spoke to your son/daughter. What was that like? How did you feel?

2. Thinking about the experience you have just shared, is it a fairly typical one? In what ways?

3. What's your relationship like with [name]? Has it always been like that?

How does being a mum / dad compare between when [name] was at home and now?"

4. Do you have any other children?

If yes – What is your relationship like with him/her/them? Has your relationship with him/her/them always been like that?

5. What diagnosis do you believe [name] has?

6. What does that diagnosis mean to you? How do you feel about their diagnosis?

How has the diagnosis affected you and your relationship?

7. Why do you think [name] has [diagnosis] [or parent's term for child's diagnosis]?

8. Many people use alcohol and drugs in their youth / young adulthood, as far as you are aware was this something your son/daughter did? If so, what was that experience like for you?

9. Many people in [redacted] have had involvement with the police or had times when they have been aggressive or violent. Has [name] ever experienced anything like this? Can you tell me a little bit about those /that time(s)? How did you react?

10. Can you tell me some of the reasons for [name] being in [redacted]? When was the first time your son/daughter received support from psychiatric services? How many times have they been treated in a mental health hospital?

11. Please tell me about what it was like for you when [name] was being admitted into [redacted]. When was your son/daughter taken into [redacted]? Had they been living with you at the time? How did it feel personally? What did you say to others about [name]?

12. In the first six months or so of [name] living at [redacted], what was it like for you?

13. Have things changed in the time since then? What's it like for you now?

14. What impact has having a child in [redacted] had on your everyday life? (work, relationships, leisure)

15. What has been your experience with mental health professionals? How do you feel about other people being involved in caregiving for your son/daughter?

16. What do you think the future holds?

17. Are there any other things you'd like to talk about that we haven't touched upon?

End of interview. Turn off tape.

- Check out how the parent is feeling, and whether any additional support is needed. Provide parent with list of support services for carers of persons with mental illness.
- Thank parent.
- Explain the tape will be transcribed and a summary of the findings written up the parent will receive a copy if they wish. Remind parents of confidentiality, they will not be identified in the final report.

Appendix 17: Adapted Self-esteem scale

Read the following questions out to the participants, and ask them to respond by EITHER saying 'Yes' or 'No'. Please ensure it is stressed that there are no right or wrong answers, it is just how they feel.

1. Do you often wish you were someone else?*	Yes	No
2. Do you like the sort of person you are?	Yes	No
3. Do you often feel ashamed of yourself?*	Yes	No
4. Do you understand yourself?	Yes	No
5. Do you think you can make a success of your life?	Yes	No
6. Are things all mixed up in your life?*	Yes	No
7. Are you pretty happy with the way you are?	Yes	No
8. Do you have a low opinion of yourself?*	Yes	No

Description: This is an 8-item measure used to evaluate levels of self-esteem. Respondents rate items on a dichotomous yes/no scale. Items are scored yes = 1, no = 0. High scores relate to high self-esteem. Missing items are given a score of 0.5. If more than one item is missing, a total scale score is not computed. Some items are reverse scored; these are indicated by an asterisk.

Origins: This questionnaire is an adapted version of Thornton, Beech & Marshall's (2004) Self-esteem Questionnaire. Items have been reworded using simpler phrasing.

References: Thornton, D., Beech, A., & Marshall, W. L. (2004). Pre-treatment self-esteem and posttreatment sexual recidivism. International Journal of Offender Therapy and Comparative Criminology, 48, 567-599.

Webster, S. D., Mann, R. E., Thornton, D., & Wakeling, H. C. (2006). Further validation of the Short Self-esteem Scale with sexual offenders. Legal and Criminological Psychology, 12, 207216.

Williams, F., Wakeling, H., & Webster, S. (2007). A psychometric study of six self-report measures for use with sexual offenders with cognitive and social functioning deficits. Psychology, Crime and Law, 13, 505-522.

Psychometric characteristics (Williams et al., 2007): Range: 0 – 8 Internal Consistency: α = .77 (N = 211)

This measure is used by Her Majesty's Prison Service, and forms part of the assessment for participation in the Adapted Sex Offender Treatment Programme. This programme was also delivered at the LD hospital where I undertook the case study

Appendix 18: Adapted Impulsivity scale

Read the following questions out to the participants, and ask them to respond by EITHER saying 'Yes' or 'No'. Please ensure it is stressed that there are no right or wrong answers, it is just how they feel.

1. Do you do and say things without thinking?	Yes	No
2. Do you get into trouble because you do things without thinking?	Yes	No
3. Do you arrive at appointments early?*	Yes	No
4. Do you do things on the spur of the moment?	Yes	No
5. Do you often speak before thinking?	Yes	No
6. Do you often get involved in things you later wish you had not got involved in?	Yes	No
7. Do you think before you act?*	Yes	No
8. Do you sometimes get carried away with ideas?	Yes	No
9. Do you need to control yourself so that you don't get into trouble?	Yes	No
10. Are you surprised by how others respond to what you do or say?	Yes	No
11. When making a decision do you think about the possible good and bad things that could happen?*	Yes	No
12. Do you make your mind up quickly?	Yes	No
13. Do you think carefully before doing things?*	Yes	No

Description: This is a 13-item scale used to measure levels of impulsiveness. The scale reflects a tendency to act without thinking about long-term consequences. Respondents rate items on a dichotomous yes/no scale. Items are scored yes = 2, no = 0, missing = 1. High scores indicate greater impulsivity. If more than one item is missing, a total scale score is not computed. Some items are reverse scored; these are indicated by an asterisk.

Origins: This scale is an adapted version of Eysenck & Eysenck's (1978) Impulsivity Scale. Nine items (1, 2, 4, 5, 6, 8, 9, 10, and 13) are adapted

from Eysenck and Eysenck's (1978) scale using simpler wording. The remaining four items were developed in-house.

Following an in-house research study examining the psychometric properties of the Adapted programmes assessment with the Adapted prison population, the removal of one item improved the construct validity and internal consistency of the measure. Therefore for scoring purposes only 12 of the 13 items are used. Item 10 is not used for scoring purposes.

References: Eysenck, S. B. G., & Eysenck, H. J. (1978). Impulsivity and venturesomeness: Their place in a dimensional system of personality description. Psychological Reports, 43, 1247-1255.

Psychometric Characteristics (Internal ISMG research report, Mathie (2008)): Range: 0 - 24 Internal Consistency: α = .82 (N = 248) Construct Validity: one factor solution Discriminant Validity: high risk men score significantly worse than lower risk men at the pretreatment stage.

This measure is used by Her Majesty's Prison Service, and forms part of the assessment for participation in the Adapted Sex Offender Treatment Programme. This programme was also delivered at the LD hospital where I completed my case study.

Appendix 19: Adapted Ruminations scale

Read the following questions out to the participants, and ask them to respond by EITHER saying 'Yes' or 'No'. Please ensure it is stressed that there are no right or wrong answers, it is just how they feel.

1. Will you always remember the bad things that have happened to you?	Yes	No
2. Do you prefer to have to wait to get your own back?	Yes	No
3. Do you forgive easily?*	Yes	No
4. Does it take you years to get rid of a grudge?	Yes	No
5. Do you always get your own back if someone wrongs you?	Yes	No
6. Do you feel so strongly about some of the things that have been done to you that you won't accept any excuse?	Yes	No
7. Do you hold grudges for a long time?	Yes	No
8. Do you keep a distance from people who annoy you?	Yes	No
9. Can you remember the last time someone insulted you?	Yes	No
10. Do you still remember the wrongs that have been done to you even after many years?	Yes	No
11. If someone harms you, are you not able to relax until you have got your own back?	Yes	No
12. When something angers you, does thinking about it make you even more angry?	Yes	No
13. Are you often sulky?	Yes	No
14. Do you find it difficult to sleep because you can't stop thinking about a wrong that has been done to you?	Yes	No
15. Do you ever help those who have done you wrong?*	Yes	No

Description: This is a 15-item scale used to measure a tendency to ruminate angrily and bear grudges. High scores reflect greater rumination. Respondents rate items on a dichotomous yes/no scale. Items are scored yes = 2, no = 0 and 1 = missing. If more than one item is missing, a total

scale score is not computed. Some items are reverse scored; these are indicated below by an asterisk.

Origins: This questionnaire is an adapted version of Capara's (1986) Dissipation-Rumination Scale. Five items were dropped from the original measure in creating the 15-item HMPS Ruminations Scale. To create the Adapted Ruminations Scale the items were reworded using simpler phrasing.

Following an in-house research study examining the psychometric properties of the Adapted programmes assessment with the Adapted prison population, the removal of a further four items improved the construct validity and internal consistency of the Adapted Ruminations Scale. Therefore for scoring purposes only 12 of the 15 items are used. Items 1, 8, 9 and 13 are not used for scoring purposes.

References: Capara, G. V. (1986). Indications of aggression: The Dissipation-Rumination Scale. Personality and Individual Differences, 7, 763-769.

Psychometric characteristics (Internal ISMG research report, Mathie (2008)): Range: 0 – 24 Internal Consistency: α = .80 (N = 248) Construct Validity: one factor solution Discriminant Validity: high risk men score significantly worse than lower risk men at the pre- and post-treatment stages.

This measure is used by Her Majesty's Prison Service, and forms part of the assessment for participation in the Adapted Sex Offender Treatment Programme. This programme was also delivered at the LD hospital where I completed my case study.

Appendix 20: Sexual Attitudes and Knowledge scale (SAKS)

The SAKS is a tool with no accredited author, that appears to have been developed specifically for people with intellectual disabilities. It consists of 19 pictures with accompanying questions on sexual knowledge and attitudes. The questions cover four areas: understanding relationships, social interactions, sexual awareness, and assertiveness. The question is read to the participant, and a score is derived for each of the 4 areas. High scores are consistent with good levels of knowledge in each area. The protocol can be used to identify learning needs in individuals to determine specific goals for one-to-one treatment. Using a modest sample (n= 34) Langdon et al. (2007) reported acceptable internal consistency for the scale (α= .82)

Appendix 21- Questionnaire offence related attitudes

SCALE ONE: RAPE AND ATTITUDES TO WOMEN.

Directions:

1. Ask the question.
2. If the response is inappropriate or not full enough (must include words or variants of the words that are underlined) then give the answer below and repeat the question – continue in this manner until you are given an appropriate response.

Question:

- "What does it mean to rape a woman?"

Appropriate response:

- When someone is forced by another person to have sexual intercourse (sex).
- If responds by saying – when a man forces (makes) a woman to have sex with him or when a man makes a woman have sex even when she says no. If says no then say that they can and repeat the original question to be answered in full.

Question No	Scale one: Rape and attitudes to women. Question	*Scoring Columns* A Items	B Items	C Items
1	Is it possible for any woman to be raped?			Yes 0
				No 1
2	Is it only women who wear tight clothes that can be raped?	Yes 1		
		No 0		
3	Could a woman wearing her Sunday best clothes be raped?	Yes 0		
		No 1		
4	Do you think that women who go around without a bra on or in tight clothes want to have sex?		Yes 1	
			No 0	
5	If a woman goes around without a bra on or in tight clothes, is she asking to be raped?			Yes 1
				No 0
6	Do you think that a woman can stop a man from raping her if she wanted to?			Yes 1
				No 0

7	Could a woman stop a man from raping her by shouting or fighting him off her?			Yes 1 No 0
8	If the rape goes ahead does that mean that she wants it?	Yes 1 No 0		

Question No	Questions Scale One Cont'd Question	Scoring Columns A Items	B Items	C Items
9	Are some women often partly to blame for the rape taking place?	Yes 1 No 0		
10	If a woman gets drunk at a party and has sex with a man there, is she fair game for anyone else?			Yes 1 No 0
11	At a party a man sees a woman going into a bedroom to have sex with another man, would it be okay then for him to force her to have sex?	Yes 1 No 0		
12	Are women just a load of bitches?	Yes 1 No 0		
13	Can women who have had sex with a lot of men still be raped?		Yes 0 No 1	
14	If a woman had sex with a lot of men is she asking to be raped?			Yes 1 No 0
15	Do women lie about being raped?			Yes 1 No 0
16	Should a man stop touching and kissing a woman when she asks him to, even if he wants to carry on?		Yes 0 No 1	
17	If a woman lets a man touch and kiss her and then suddenly says she wants him to stop, is it ok for him to keep going?		Yes 1 No 0	
18	Can you show a woman that you love her by forcing her to have sex with you?	Yes 1 No 0		
19	Is it ok to force a woman to have sex?			Yes 1

				No 0
20	If a man rapes a woman is it just a bit of fun?	Yes 1		
		No 0		
21	Do men rape women to scare or frighten them?		Yes 0	
			No 1	
22	Do men rape women to gain power over them?		Yes 0	
			No 1	
23	Do women make too much fuss about sexual assault?	Yes 1		
		No 0		
24	Do you think that if a woman is raped that it would cause her any harm?	Yes 0		
		No 1		
25	If a woman was raped do you think that it would take a few weeks or longer to get over it?	Weeks 1		
		Longer 0		
	Total Item Columns A, B, & C.			

SCALE TWO: VOYEURISM.

Question No	Scale Two: Voyeurism Question	Scoring Columns A Items	B Items	**C Items**
26	Do women who don't close their curtains when they are in their underwear want people to look at them?	Yes 1		
		No 0		
27	Do some women like men to stare at their bodies?	Yes 1		
		No 0		
28	Do women feel attractive when men stare at their bodies?			Yes 1
				No 0
29	If a woman has a big pair of boobs is it alright to have a good look?	Yes 1		
		No 0		

30	If a woman is wearing a short skirt does it mean that she wants men to look up it?	Yes 1		
		No 0		
31	Is staring at a woman's body a good way of showing her that you find her attractive?	Yes 1		
		No 0		
32	Do men stare at women to scare them?		Yes 0	
			No 1	
33	If a man stares at a woman is he just having a bit of fun?	Yes 1		
		No 0		
34	Is it ok to stare at a woman if you don't touch her?	Yes 1		
		No 0		
35	If a woman sees a man staring at her do you think that she would only be upset about it for a few minutes or longer?	Few mins 1		
		Longer 0		
	Total Item Columns A, B, & C.			

SCALE THREE: EXHIBITIONISM.

Directions:

1. Ask the question.
2. If the response is inappropriate or not full enough (must include words or variants of the word that are underlined) then give the answer below and repeat the question – continue in this manner until you are given an appropriate response.

Question:

- "What does it mean to flash?"

Appropriate response:

- When a man shows (exposes) his private parts (penis) in public. Accept any appropriate or colloquial wording.

Question No	Scale Three: Exhibitionism Question	Scoring Columns A Items	B Items	C Items
36	If a woman looks at a flasher is it her fault?		Yes 1	
			No 0	
37	Is it the mans fault if a woman looks at him when he flashes?			Yes 0
				No 1
38	Do women just pretend to be shocked when they see a penis?	Yes 1		
		No 0		
39	When a man shows his penis to a woman does it really turn her on?	Yes 1		
		No 0		
40	Do most women laugh about being flashed at?	Yes 1		
		No 0		
41	Do women think that it is a bit of fun to be flashed at?	Yes 1		
		No 0		
42	Is flashing at someone a good way to show women that you want to have sex?	Yes 1		
		No 0		
43	Do men flash to scare women?		Yes 0	
			No 1	
44	Do men enjoy scaring women by flashing at them?		Yes 0	
			No 1	
45	Do you think that a woman would be harmed by a man flashing at her?		Yes 0	
			No 1	
46	Do you think that it would take a woman years or a few days to get over being flashed at?			Few Days 1
				Few Years 0
	Total Item Columns A, B, & C.			

SCALE FOUR: STALKING AND SEXUAL HARRASSMENT

Question No	Scale Four: Stalking and Sexual Harassment Questions	Scoring Columns A Items	B Items	C Items
87	Is following a woman a good way to show her you like her?	Yes 1		
		No 0		
88	Do some women make up stories about men following them?		Yes 1	
			No 0	
89	Do men follow women because they think they have power over them?		Yes 0	
			No 1	
90	If a woman is walking around the town is it ok for a man to follow her?	Yes 1		
		No 0		
91	Do some women like men to follow them?	Yes 1		
		No 0		
92	Does it make women feel attractive if men follow them?	Yes 1		
		No 0		
93	Is it ok to follow women as long as you don't touch them?		Yes 1	
			No 0	
94	Is there any harm in following women?	Yes 0		
		No 1		
95	If a woman is wearing a short skirt and no bra does she want a man to follow her?	Yes 1		
		No 0		
96	Could a woman stop a man from following her if she wanted to?		Yes 1	
			No 0	
97	Is following a woman a good way of showing her you would like to have sex with her?	Yes 1		
		No 0		

98	Do men follow women because they want to scare them?	Yes 0		
		No 1		
99	If a man follows a woman is he just having a bit of fun?	Yes 1		
		No 0		
100	If you followed a woman would it turn her on?	Yes 1		
		No 0		
101	Would a woman get upset if she saw a man following her?		Yes 0	
			No 1	
102	If she got upset how long would it take her to get over it – a couple of days, a few weeks/longer?		Days 1	
			Weeks/ Longer 0	
	Total Item Columns A, B, & C.			

SCALE FIVE: DATING ABUSE.

Question No	Scale Five: Dating Abuse Question	Scoring Columns A Items	B Items	C Items
47	Is it ok to kiss in public, on the street?		Yes 0	
			No 1	
48	Do you think a woman should expect a man to try it on, on a date?	Yes 1		
		No 0		
49	If a girl invites you back to her place for a coffee is she really offering to have sex?	Yes 1		
		No 0		
50	If you ask a girl out for a date should she know that you want to have sex?	Yes 1		
		No 0		
51	Do you think its okay to expect sex on the first date?	Yes 1		
		No 0		

52	If you are on the first date is it okay to expect the girl to have sex with you?			Yes 1
				No 0
53	If a girl makes out that she does not want to kiss is she playing a game?	Yes 1		
		No 0		
54	Would a woman think that you found her ugly if you didn't ask her to have sex with you?	Yes 1		
		No 0		
55	If you don't ask a woman to have sex will she think that you don't like her?	Yes 1		
		No 0		
56	Do you think a woman would get upset if her boyfriend kept trying to encourage her to have sex even though she already said no?	Yes 0		
		No 1		
	Total Item Columns A, B, & C.			

SCALE SIX: HOMOSEXUAL ASSAULT.

Directions:

1. Ask the question.
2. If the response is inappropriate or not full enough (must include word or variants of the words that are underlined) then give the answer below and repeat the question – continue in this manner until you are given an appropriate response.

Question:

- "What does it mean to be homosexual / gay?"

Appropriate response:

- When a man or woman is sexually attracted to members of the same sex. Also accept – when a man is attracted or has sex with another man.

Question:

- What would it mean to rape a man?

Appropriate response:

- When a man forces (makes) another man to have sex with him.

Question No	Scale Six: Homosexual Assault **Question**	Scoring Columns A Items	B Items	**C Items**
57	Is it ok for men to have sex together?		Yes 0	
			No 1	
58	If a man approached you for sex would you hit him or tell him you are not gay?			Hit 1
				Tell 0
59	If a man does not want to have sex can he be forced to by another man?			Yes 0
				No 1
60	If a man does not try to fight his way out of a rape does he want to have sex?			Yes 1
				No 0
61	Could a man stop another man from raping him?			Yes 1
				No 0
62	Do men just say that they were raped because they are ashamed of being gay?		Yes 1	
			No 0	
63	If a man forced another man to have sex would that be a good way of showing that he found him attractive?		Yes 1	
			No 0	
64	Would a man rape another man to scare him?	Yes 0		
		No 1		
65	Would a man rape another man to get power over him?	Yes 0		
		No 1		
66	If a man is raped by another man does it cause him harm?	Yes 0		
		No 1		
67	If a man tried to force another man or boy to have sex is he just having a bit of fun?	Yes 1		
		No 0		
68	Would it take a man a few weeks or longer to get over being raped?	Few weeks 1		
		Longer 0		

	Total Item Columns A, B, & C.			

SCALE SEVEN: OFFENCES AGAINST CHILDREN.

Directions:

1. Ask the question.
2. If the response is inappropriate or not in full enough (must include words or variants of the words that are underlined) then give the answer below and repeat the question – continue in this manner until you are given an appropriate response.

A. Question:

- "What does it mean to masturbate?"

Appropriate response:

- When a person feels sexy (turned on) they may play with their private parts. Also accept – when a man plays with his penis or any other appropriate colloquial response.

B. Question:

- "What does it mean to have a period?"

Appropriate response:

- When girls are between approximately 11 – 13 years of age, each month blood from their womb comes out through their vagina (between their legs etc). If does not state age, frequency or where the blood comes from then ask. If unable to answer then give the correct answer and ask the question again.

C. Question:

- "What does it mean to sexually abuse a child?"

Appropriate response:

- When a child is touched or kissed inappropriately; made to have sexual intercourse or any other kind of sex. Accept any of the underlined answers and any other appropriate colloquial response.

Question **No**	Scale seven: Offences against children Questions	Scoring Columns A Items	B Items	C **Items**
69	Do some children enjoy having sex with men?	Yes 1		
		No 0		
70			Yes 1	

	Do some children make up stories about being sexually abused?		No 0	
71	Do children lead men on sexually?	Yes 1		
		No 0		
72	Do children do sexy things so that men will get turned on and want to have sex with them?	Yes 1		
		No 0		
73	Is it wrong to force a child to have sex?			Yes 0
				No 1
74	Can children be abused by people they know as well as strangers?	Yes 0		
		No 1		
75	Can a child be abused by family members like their father, their mother or their uncle?	Yes 0		
		No 1		
76	Can you show you love a child by having sex with them?	Yes 1		
		No 0		

Question No	Scale Seven: Offences against children Cont'd Questions	Scoring Columns		
		A Items	**B Items**	**C Items**
77	Do men have sex with children to scare them?		Yes 0	
			No 1	
78	If a man has sex or masturbates in front of a child is it just a bit of fun?	Yes 1		
		No 0		
79	If a girl is old enough to have periods is she old enough to have sex?	Yes 1		
		No 0		
80	Can a ten year old decide whether to have sex or not?		Yes 1	
			No 0	
81	If a child was ten years old would they be able to decide to have sex with a man?			Yes 1
				No 0
82		Yes 0		

	Do you think sex with children does harm if the adult is gentle?	No 1		
83	If the man is gentle would sex cause harm to the child?			Yes 0
				No 1
84	Does making a child watch you masturbate do them any harm?	Yes 0		
		No 1		
85	After a few years would a child get over being sexually abused?	Yes 1		
		No 0		
86	Would a child ever fully get over being sexually abused or would they be okay in a few weeks or years?	Few weeks/ Years 1		
		Never 0		
	Total Item Columns A, B, & C.			

Question No	Scale Eight: Social Desirability **Question**	Scoring Columns *YES*	*NO*
103	Do some women lead men on?	1	0
104	If a woman has a big pair of boobs is it only natural to have a good look?	1	0
105	Do some women make up stories about men looking through curtains at them?	1	0
106	Do you think a woman has to look when a man flashes at her?	0	1
107	Could a woman walk away when a man flashes at her?	1	0
	Total Item Columns Social Desirability		

The QACSO is a questionnaire specifically designed for use with sex offenders who have intellectual disabilities. This protocol is designed to measure cognitive distortions commonly expressed by sexual offenders across eight domains: Rape and Attitudes to Women, Voyeurism, Exhibitionism, Dating Abuse, Homosexual Assault, Offences against Children, Stalking and Sexual Harassment and Social Desirability. The QACSO has been standardized on sexual offenders with intellectual disabilities, non-sexual offenders with intellectual disabilities, non-offenders with intellectual disability and mainstream males. The measure has been shown to discriminate sexual offenders with intellectual disabilities from non-offenders indicating particular cognitive distortions which facilitate offending behaviour in sexual offenders. The QACSO has adequate test-retest reliability for all groups with the exception of 'rape' and 'attitudes towards women' for non-sexual offenders without learning disabilities. The measure has good internal reliability and construct validity. The QACSO can be used to assess individuals who have been identified as at risk of offending sexually and to reassess individuals who attend treatment to identify risk of re-offending. The measure can also be used for research purposes examining core themes and attitudes held by offenders (Broxholme & Lindsay, 2003; Lindsay, Whitefield & Carson, 2007). Internal consistency of each scale revealed alphas of around 0.8.

In addition to discriminating between groups, the protocol has been used to monitor treatment progress (Lindsay & Smith, 1998; Rose, Jenkins, O'Connor, Jones & Felce, 2002; Murphy & Sinclair, 2009). There is also some preliminary evidence that the QACSO may differentiate between offenders against children and offenders against adults, with the latter scoring significantly lower on offences against children scale (Lindsay, Michie, Whitefield, Martin, Grieve & Carson, 2006). The psychometric properties of the QACSO were recently cross validated in two studies (ibid.) In both studies, the offenders against adults reported higher levels of attitudes consistent with sexual offenders in the area of rap and attitudes to women. In both studies, offenders against children reported significantly higher levels of cognitive distortions in the area of offences against children.

In a study that compared treated and untreated sex offenders with intellectual disabilities, Langdon and Talbot (2006) found that the treatment group had significantly fewer cognitive distortions as measured by the QACSO when compared to a no treatment group. They felt that the results suggested psychological treatment was effective in reducing levels of cognitive distortions. The scale has also demonstrated its ability to assess change in pro-sexual assault attitudes towards sexual behaviour following cognitive-behavioural intervention for men with intellectual disabilities (Murphy, Sinclair, Hays, Heaton & SOTSEC-ID, 2006; Murphy, Powell, Guzman & Hays, 2007).

Appendix 22: Family Relations Test Items for Older Children

Mild positive (affectionate) feelings coming from child

00 This person in the family is very nice.

01 This person in the family is very jolly.

02 This person in the family always helps the others.

03 This person in the family has the nicest ways.

04 This person in the family never lets you down.

05 This person in the family is lots of fun.

06 This person in the family deserves a nice present.

07 This person in the family is a good sport.

08 This person in the family is very nice to play with.

09 This person in the family is very kind-hearted.

Strong positive (sexualised) feelings coming from child

10 I like to cuddle this person in the family.

11 I like to be kissed by this person in the family.

12 I sometimes wish I could sleep in the same bed as this person in the family.

13 I wish I could keep this person near me always.

14 I wish this person in the family would care for me more than anybody else.

15 When I get married I want to marry somebody who is just like this person in the family.

16 I like this person in the family to tickle me.

17 I like to hug this person in the family.

Mild negative feelings coming from the child

20 This person in the family is sometimes a bit too fussy.

21 This person in the family nags sometimes.

22 This person in the family sometimes spoils other people's fun.

23 This person in the family is sometimes quick-tempered.

24 This person in the family is sometimes bad-tempered.

25 This person in the family complains too much.

26 This person in the family is sometimes annoyed with good reason.

27 This person in the family is never satisfied.

28 This person in the family is sometimes not very patient.

29 This person in the family sometimes gets too angry.

Strong negative (hostile) feelings coming from the child

30 Sometimes I would like to kill this person in the family.

31 Sometimes I wish this person in the family would go away.

32 Sometimes I hate this person in the family.

33 Sometimes I feel like hitting this person in the family.

34 Sometimes I think I would be happier if this person was not in our family.

35 Sometimes I am fed up with this person in the family.

36 Sometimes I want to do things just to annoy this person in the family.

37 This person in the family can make me feel very angry.

Mild positive (affectionate) feelings going towards child

40 This person in the family is kind to me.

41 This person in the family is very nice to me.

42 This person in the family likes me very much.

43 This person in the family pays attention to me.

44 This person in the family likes to help me.

45 This person in the family likes to play with me.

46 This person in the family really understands me.

47 This person in the family listens to what I have to say.

Strong positive (sexualised) feelings going towards the child

50 This person in the family likes to kiss me.

51 This person in the family likes to hug me.

52 This person in the family likes to cuddle me.

53 This person in the family likes to help me with my bath.

54 This person in the family likes to tickle me.

55 This person in the family likes to be in bed with me.

56 This person in the family always wants to be with me.

57 This person in the family cares more for me than for anybody else.

Mild negative feelings going towards the child

60 This person in the family sometimes frowns at me.

61 This person in the family likes to tease me.

62 This person in the family sometimes tells me off.

63 This person in the family won't play with me when I would like it.

64 This person in the family won't always help me when I am in trouble.

65 This person in the family sometimes nags at me.

66 This person in the family sometimes gets angry at me.

67 This person in the family is too busy to have time for me.

Strong negative (hostile) feelings going towards the child

70 This person in the family hits me a lot.

71 This person in the family punishes me too often.

72 This person in the family makes me feel silly.

73 This person in the family makes me feel afraid.

74 This person in the family is mean to me.

75 This person in the family makes me feel unhappy.

76 This person in the family is always complaining about me.

77 This person in the family does not love me enough.

Maternal over-protection

80 Mother worries that this person in the family might catch cold.

81 Mother worries that this person in the family might get ill.

82 Mother worries that this person in the family might get run over.

83 Mother worries that this person in the family might get hurt.

84 Mother worries that something might happen to this person in the family.

85 Mother is afraid to let this person in the family run about too much.

86 Mother is afraid to let this person in the family play with rough children.

87 Mother worries that this person in the family doesn't eat enough.

Paternal over-indulgence

90 This is the person in the family father makes a big fuss about.

91 This is the person in the family father pays too much attention to.

92 This is the person in the family father spoils too much.

93 This is the person in the family father spends too much time with.

94 This is the person in the family father likes best.

Maternal over-indulgence

95 This is the person in the family mother makes a big fuss about.

96 This is the person in the family mother pays too much attention to.

97 This is the person in the family mother spoils too much.

98 This is the person in the family mother spends too much time with.

99 This is the person in the family mother likes best.

An unpublished master's dissertation by Nemtin (1979) explored emotional attitudes of adolescents with a learning disability, to discover their perception of feeling toward various members of their family and to estimate their perceptions of the family member's reciprocal regard for him/her. The Family Relations Test was used for this purpose. The participant sample consisted of 15 boys and 15 girls, ranging in age from 13 to 18 years, who were randomly chosen from a population of 65 learning disabled adolescents receiving 'special education'. The number of participant's siblings varied from 1 to 5. Nemtin's (1979) study results indicated that both male and female adolescents with a learning disability have positive feelings towards their mothers and perceive her as being a warm and affectionate person. The boys showed very little aggression or hostility towards their fathers, while the girls were involved with their father in terms of affectionate, sexual and negative feeling responses. The perception of the self by adolescents with a learning disability was an ambivalent one, that vacillated between positive and negative self-esteem. Towards their siblings, the adolescents with learning disability displaced aggression and hostility. Projected into the nobody figure were the strong sexual and negative feelings of the learning disabled adolescent. Nemtin (1979) concluded the Family Relations Test demonstrated utility in discriminating differences in the perceived emotional family relationships of adolescents with a learning disability.

Appendix 23- Working in partnership with psychiatrists and carers: Leaflet produced by Royal College of Psychiatrists and Princess Royal Trust for Carers, July 2010.

Working together to make a real difference

Partners in Care

working in partnership with psychiatrists and carers

Introduction

This leaflet is written for:

- carers who provide help and support, without pay, to a relative, partner or friend, who is being assessed or treated by forensic psychiatric services;
- psychiatrists and other members of forensic psychiatric teams who provide care and treatment for people within these services.

It suggests ways of improving communication that allow mutual respect and a working partnership to develop from the first contact with forensic psychiatric services.

For the carer

About forensic psychiatric services

Forensic psychiatric services specialise in the assessment and treatment of people with mental disorders undergoing legal or court proceedings, or who have offended.

However, people with mental disorders, who have never been involved with the criminal justice system, might also be treated in forensic psychiatric services, if they cannot be safely managed elsewhere. Treatable mental disorders include mental illness, personality disorders and learning disabilities.

The NHS provides forensic psychiatric services in healthcare and penal settings, including secure psychiatric hospitals, the courts, prisons and young offenders' institutions. Private forensic healthcare mainly provides long-stay services.

Forensic psychiatric units have different levels of security ranging from low or medium to high secure hospitals. Most patients are detained under mental health legislation, which differs in each jurisdiction of the United Kingdom and Ireland.

Psychiatric services for offenders or those accused of offending

People with mental disorders do not necessarily have to stay in the legal or judicial system. They can be transferred to the healthcare system, at the time of arrest, during court proceedings or during prison sentence.

Referral to psychiatric services can be made by a GP, other doctors, mental health professionals, police, legal professionals, courts and prison staff.

A psychiatrist and/or members of a mental health team will usually make an assessment and recommendations. They may use mental health legislation as part of the process.

Lawyers and others can commission a psychiatric report, which is paid for by the person or organisation requesting it. Psychiatric reports can only be prepared with the consent of the person concerned who must be aware that it could be given to others, including the court. Psychiatric reports usually contain an opinion and recommendations, which can affect the outcome of the legal or court processes and future psychiatric care.

Forensic psychiatric services are more likely to become involved if:

- mental health or legal issues are complex
- the offence was serious and warrants a custodial sentence
- the person might need admission to a secure psychiatric hospital
- expertise is required in the care of mentally disordered offenders

Information about the options and mental health legislation can be obtained from voluntary sector organisations (see Further Help).

Carers issues

At any stage, carers can alert the police, the courts, lawyers and health professionals to concerns about someone's mental health, care and treatment. This is important when the person is vulnerable, affected by a mental disorder, presents a risk to themselves or others, or where there are concerns about the administration of medication. Carers may wish to keep in touch with healthcare and legal professionals and give their contact details.

Carers of people involved with legal or court proceedings share similar concerns with other carers, but can have additional ones:

- they or other family members may have been victims of the offender
- the nature or severity of the offence may have upset the carer
- carers can be stigmatised by the offence and have to move home
- the carer may be excluded from the legal process
- the person may not wish the carer to be involved with their healthcare
- forensic services are often regional and can be far away from the carer's home.

As a carer, you may feel:

- ashamed or guilty about the offence or the challenging behaviour
- confused about the medical and legal systems
- worried about the long-term outcome for the person
- worried about financial matters and how you will get help
- worried about the effect on you and the rest of the family
- worried about the circumstances in the hospital or prison.

Tips for Carers

In partnership with your doctor and members of the forensic service team

Forming a positive relationship with all the staff and doctors involved in the care of a patient is important if the condition is long-term. Good communication between the psychiatrist, members of the forensic service team, the patient and the carer are important, but take time and effort.

The specialists you are likely to come across are: psychiatrists, psychologists, psychotherapists, psychiatric nurses, social workers and occupational therapists.

Questions to ask the doctor

☐	**What is the diagnosis?**
☐	**Can you explain it in terms that I can understand?**
☐	**Do you have any written material on this disorder? If not, who does?**
☐	**Are there any treatments?**
☐	**Where can I get information about medication and the possible side-effects?**
☐	**How long will it take for the medication to work?**
☐	**Will there be opportunities for the patient to exercise, have education and work?**
☐	**Can they have therapy to reduce the risk of re-offending?**

☐	**Who will look after the patient's physical health?**
☐	**Are there any plans for assessment by other professionals or services?**
☐	**How long will it be before they can leave secure facilities?**
☐	**Are they still involved in the criminal justice system?**
☐	**Will they need to go back to court?**
☐	**Will they remain in hospital or could they be transferred back to prison?**
☐	**Will they have to stay in this hospital or could they be moved to a hospital closer to home?**
☐	**How do I arrange to visit?**
☐	**Can I attend reviews of clinical care?**
☐	**How can I find out about the offence?**
☐	**Are there any organisations or community services that can help me?**
☐	**Which health service worker is my main contact for guidance and advice?**
☐	**How often should I come and see you? Can we have family or support therapy?**
☐	**This person has children – how do I arrange for them to visit?**

Remember to arrange your next appointment before you leave. Regular well prepared visits to the doctor or other members of the forensic psychiatric services team will help get the best care.

Advice to help you to prepare for your visits

Find out about visiting arrangements and book in advance. You may have to be registered and show photo-identification on arrival. There are restrictions on the items you can bring into secure areas, (e.g. a mobile phone). Allow plenty of time for the security procedures, as you may be searched.

During your visit:

If you do not understand something, ask questions. Do not be afraid to speak up. It may be helpful to take notes and check that there are no misunderstandings.

For follow-up visits

Review the information from your last visit and write down any questions or concerns you have had since then. This will help you to concentrate on the things that matter most. Your concerns may include questions about:

- changes in symptoms
- side-effects of medication
- general health of the patient
- your own health
- additional help needed

Further tips for carers when dealing with doctors and other members of the forensic service team

Doctors and healthcare professionals may be reluctant to discuss a person's diagnosis or treatment with the carer. There is a duty of confidentiality between the doctor and the patient. If the person is too ill to understand what is happening, doctors might involve the carer in discussions and decisions. (*See our leaflet 'Carers and confidentiality in mental health'*).

If the doctor is unwilling to involve you as the carer, you can

- ask the person if you can stay with them at some or for part of their interview
- talk with other carers as they may have some helpful suggestions
- talk to other members of the forensic service team
- contact carers' organisations in the voluntary sector or the social worker
- ask if there is a carers' support group for the forensic service.

Don't forget to take care of yourself and make time for you. It is important that you talk about your worries and don't struggle alone. Try to keep in

touch with friends. If you live in England, you may be entitled to a carer's assessment to identify your needs. This can be arranged through your doctor or a member of the mental health team. They should also be able to refer you to a local carers' support organisation.

For the professional

As a professional working with people in forensic psychiatric services, we hope that the following is a helpful guide to good practice.

		When making an assessment, do you?
☐		**See the person with the mental disorder and the carer separately, as well as together**
☐		**Collect collateral information**
		Do you allow yourself enough time to?
☐		**Obtain and read the background information**
☐		**Take a comprehensive history**
☐		**Leave time for questions and discussion**
☐		**Explain how you arrived at the diagnosis**
☐		**Talk about the prognosis**
		In the management of the mental illness or disability, do you?
☐		**Discuss possible treatments**
☐		**Talk about the possible side-effects of medication**
☐		**Spend time asking about the carer's health – physical and emotional**
☐		**Discuss how to meet the needs of both carer and the patient**

Points to remember

- Everyone needs some respite
- Make it clear that you will be happy to talk to other members of the family
- Refer everyone that you see to a relevant mental health or carers' organisation
- Make it clear that someone will always be available
- Give an out-of-hours telephone number
- Make sure that there is a named professional person whom the family can contact at any time
- When you write your letter to the GP or other professionals, consider sending a copy to the patient and the carer
- Try to talk to other professionals on the telephone, as well as writing
- Make sure that the patient and carer have adequate information about the care and treatment

Further help

MIND Mindinfoline: 0845 766 0163;

Legal advice service: 0845 225 9393. Publishes a guide to mental health and the courts.

Rethink National Advice Service: 020 8840 3188 or 0845 456 0455 Publishes information and advice on offenders with mental illness.

The Institute of Mental Health Act Practitioners Provides useful guidance and information on the Mental Health Acts.

The Law Society General Enquiries tel: 020 7242 1222 Publishes information on finding a legal representative.

The Princess Royal Trust for Carers Email: support@carers.org Provides information, support and advice to carers.

This leaflet was produced as part of the Partners in Care campaign, a joint initiative between the Royal College of Psychiatrists and The Princess Royal Trust for Carers.

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