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“At the end of the day he’s still my son”: An Interpretative Phenomenological Analysis of mothers’ experiences of having a son in Forensic Mental Health Services.

& Clinical Research Portfolio

Fiona Scott, BSc (Hons), MSc

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Institute of Health and Wellbeing
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University of Glasgow

September 2017

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Firstly, I would like to express enormous gratitude to all the participants who kindly gave up their time and shared their experiences with me. Without them, this research would never have been possible.

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Particular thanks go to Kevin Jamieson and Maureen Black for assisting with recruitment within the carers group.

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# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Chapter 1: Systematic Review</strong></td>
<td>4-39</td>
</tr>
<tr>
<td></td>
<td>What factors are associated with Ward Atmosphere in Forensic Settings? A Systematic Review</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Chapter 2: Major Research Project</strong></td>
<td>40-76</td>
</tr>
<tr>
<td></td>
<td>“At the end of the day he’s still my son”: An Interpretative Phenomenological Analysis of mothers’ experiences of having a son in Forensic Mental Health Services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Appendices</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 1 - Summary of Author Guidelines for Submission to the Journal of Forensic Psychiatry and Psychology</td>
<td>77-82</td>
</tr>
<tr>
<td></td>
<td><strong>Systematic Review</strong></td>
<td>83</td>
</tr>
<tr>
<td></td>
<td>Appendix 2- Risk of Bias Tool</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 3- Detailed breakdown of Risk of Bias ratings</td>
<td>84-89</td>
</tr>
<tr>
<td></td>
<td><strong>Major Research Project</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appendix 4- Ethics Approval letter and Amendments</td>
<td>90-93</td>
</tr>
<tr>
<td></td>
<td>Appendix 5- NHS R&amp;D Approval letter and Amendments</td>
<td>94-98</td>
</tr>
<tr>
<td></td>
<td>Appendix 6- Participant Information Sheet</td>
<td>99-102</td>
</tr>
<tr>
<td></td>
<td>Appendix 7- Staff Information Sheet</td>
<td>103-105</td>
</tr>
<tr>
<td></td>
<td>Appendix 8- Recruitment Poster</td>
<td>106</td>
</tr>
<tr>
<td></td>
<td>Appendix 9- Participant Consent Form</td>
<td>107</td>
</tr>
<tr>
<td></td>
<td>Appendix 10- Interview Schedule</td>
<td>108-109</td>
</tr>
<tr>
<td></td>
<td>Appendix -11 Sample of Analysed Transcription</td>
<td>110-111</td>
</tr>
<tr>
<td></td>
<td>Appendix – 12 Sample Themes and Exemplars</td>
<td>112-114</td>
</tr>
<tr>
<td></td>
<td>Appendix -13 Major Research Proposal</td>
<td>115-128</td>
</tr>
</tbody>
</table>

What factors are associated with Ward Atmosphere in Forensic Settings? A Systematic Review

“At the end of the day he’s still my son”: An Interpretative Phenomenological Analysis of mothers’ experiences of having a son in Forensic Mental Health Services.

Appendices

Appendix 1 - Summary of Author Guidelines for Submission to the Journal of Forensic Psychiatry and Psychology

**Systematic Review**

Appendix 2- Risk of Bias Tool
Appendix 3- Detailed breakdown of Risk of Bias ratings

**Major Research Project**

Appendix 4- Ethics Approval letter and Amendments
Appendix 5- NHS R&D Approval letter and Amendments
Appendix 6- Participant Information Sheet
Appendix 7- Staff Information Sheet
Appendix 8- Recruitment Poster
Appendix 9- Participant Consent Form
Appendix 10- Interview Schedule
Appendix -11 Sample of Analysed Transcription
Appendix – 12 Sample Themes and Exemplars
Appendix -13 Major Research Proposal
CHAPTER ONE
SYSTEMATIC REVIEW

What Factors are Associated with Ward Atmosphere in Forensic Mental Health Settings?
A Systematic Review

Fiona Scott*

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Word count (including abstract and references): 7225

Written according to guidelines for submission to The Journal of Forensic Psychiatry and Psychology
(See Appendix 1 for a summary of author instructions).

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Submitted in partial fulfilment of the requirement for the degree of Doctorate in Clinical Psychology (DClinPsy)
What Factors are Associated with Ward Atmosphere in Forensic Mental Health Settings? A Systematic Review

Abstract

Background: It is well established that an individual’s interpersonal environment can impact upon their wellbeing and recovery from mental ill health. Within forensic mental health services, an individual’s environment often includes inpatient settings. This can be understood as the social milieu or ward-atmosphere. It is important that we can identify and understand the key correlates of ward-atmosphere so that services can provide the best quality of care for individuals.

Aims: The aim of this review was to systematically identify, synthesise and assess risk of bias in research exploring service user factors associated with ward-atmosphere in forensic mental health settings.

Methods: Nine computerised databases (Cochrane Library, OVID Medline, OVID Embase, EBSCO CINAHL, EBSCO Psychinfo, EBSCO Psycharticles, EBSCO Psychology and Behavioral Sciences Collection, Web of Science and Google Scholar were searched from the start date of the respective database to 19\textsuperscript{th} February 2017.

Results: Eight studies met inclusion criteria and were assessed to determine their risk of bias. Service user factors found to be positively associated with ward-atmosphere included: service attachment, therapeutic alliance, recovery oriented care, motivation, satisfaction, diagnosis of personality disorder, diagnosis of psychosis, interpersonal problems and levels of historical risk. Negative associations were found between ward-atmosphere and: Attachment avoidance, depression, overall levels of risk, current levels of risk and antisocial behaviour.

Applications: Further research should aim to further replicate the results while addressing the inherent methodological limitations. Having a better knowledge of the correlates of
ward-atmosphere will develop our understanding of how it can be managed or changed, in order to ensure that service users have an effective therapeutic environment that can facilitate wellbeing and recovery.

**Key words:** forensic psychiatry, milieu, ward atmosphere, recovery
**Introduction**

Research has shown that one of the most influential factors determining the course of a psychosis is an individual’s family and interpersonal environment (Brown, Carstairs & Topping, 1958; Brown, Monck, Carstairs & Wing, 1962). The importance of a person’s interpersonal environment as a context for recovery extends to their experience of mental health services. This might include experiences of individual staff, a particular team, but also the physical environment and the system as a whole. As early as 1953, the World Health Organization suggested that “the most important single factor in the efficacy of the treatment given in a mental hospital appears to the committee to be an intangible element which can only be described as its atmosphere” (WHO, 1953, pg 17). Moos and colleagues were among the first to examine ward-atmosphere within inpatient hospital settings and conceptualised it as comprising of the individual, the setting and the individual and setting interaction (Moos & Houts, 1968).

Moos (1974) attempted to operationalise the phenomenon and developed the Ward Atmosphere Scale (WAS). Using the WAS, Moos, Shelton and Petty (1973), found that “wards that were most successful in keeping patients out of the hospital emphasized autonomy and independence, a practical orientation, order and organization, and a reasonable degree of staff control. In addition, they emphasized a personal problem orientation and the free and open expression of anger” (pg 296). Research has since provided support for this finding (Friis, 1986a; Rossberg & Friis, 2003b; Rossberg, Melle, Opjordsmoen & Friis, 2006; Jansson & Eklund, 2002b).

There is now a body of evidence to suggest that ward-atmosphere can influence various service user outcomes including response to medication (Kellam, Goldberg, Schooler, Berman & Shmelzer, 1967), satisfaction (Gjerden & Moen, 2001; Middelboe, Schodt,
Byrsting, & Gjerris, 2001; Rossberg & Friis, 2004), post-discharge adjustment in the community (Collins, Ellsworth, Casey, Hyer, Hickey, Schoonover, Twemlow & Nesselroade, 1985), psychiatric symptoms (Eklund & Hansson, 1997; Oshima, Mino & Inomata, 2005; Cohen & Khan, 1990; Jin, 1994; Fan, Huang, Wu & Jiang, 1994), post hospital functioning (Klass, Glenn, Growe & Strizich, 1977), motivation (Eklund & Hansson, 2001) and quality of life (Eklund & Hansson, 1997). Having a better understanding of these can in turn inform service provision in order to improve outcomes for service users.

**Forensic Settings**

There is a growing body of research investigating ward-atmosphere in forensic settings (Brunt, 2008; Brunt & Rask, 2007; Tonkin, 2012; Cruser, 1995; Morrison, Burnard & Philips, 1997; Goldmeier & Silver, 1988). In forensic inpatient services there is an added dimension of complexity (compared to general psychiatric services) whereby services must manage the balance of creating a therapeutic environment which promotes recovery and provides its residents with the best possible care while considering factors relating to risk, security, detention, legal processes and protection of the public. This added level of complexity and the potential conflict between duty of care to the person and duty of protection to the public can further impact upon ward-atmosphere (Brunt & Rask, 2005; Moos, 1989).

Robinson, Craig and Tonkin (2016) recently completed a systematic review to examine the relationship between perceptions of ward-atmosphere and aggressive behaviour in forensic services. In reviewing the 7 included studies, they found that more open the institutional climate, the level of patient cohesion, patients/inmates feelings of safety, and atmosphere of the environment were the factors found to be associated with increased levels of
aggression. The review by Robinson et al. (2016) has been able to give clarity about the relationship between ward-atmosphere and aggression however there are likely to be a range of factors related to ward-atmosphere and understanding these relationships could enhance interventions to improve ward-atmosphere. Therefore, the current review aimed to identify and synthesise the current research investigating ward-atmosphere in forensic settings and also assess the risk of bias of this literature.

Questions:

1) What are the characteristics of the studies, which examine service user factors and their association with ward-atmosphere in forensic mental health settings?

2) What service user factors are associated with ward-atmosphere in forensic mental health settings?

3) What methodological features are associated with increased risk of bias?

Method

Search Strategy:

The following online databases were systematically searched for relevant articles examining ward-atmosphere in forensic settings Cochrane Library, OVID Medline, OVID Embase, EBSCO CINAHL, EBSCO Psychinfo, EBSCO Psycharticles , EBSCO Psychology and Behavioral Sciences Collection, Web of Science and Google Scholar. Databases were searched from their respective start date to 19th February 2017. The following search terms were used: “ward atmosphere” OR “ward climate” OR “ward environment” OR “ward milieu” OR “social climate” OR “therapeutic milieu” OR “therapeutic environment” AND forensic OR secur*. Online titles and abstracts were
reviewed and duplicates were removed. Articles were then examined to determine if they met eligibility criteria. The full text of potentially eligible papers were obtained. Hand searches of review papers were also conducted to identify any eligible studies. The reference section of papers that were identified by the electronic database searches were inspected to identify additional studies to be included in the review.

**Inclusion and Exclusion Criteria:**

Articles identified by the search strategy were screened using the following criteria:

**Inclusion criteria**

- Journal article published in a peer reviewed journal
- Written in English
- Studies conducted in inpatient forensic adult mental health settings
- Studies utilising a quantitative methodology

**Exclusion Criteria**

- Review articles, books, book chapters and conference papers.
- Commentaries/descriptions, case studies/reports/unpublished theses/policy documents.
- Studies examining only service user perceptions of ward-atmosphere without including their associations with ward-atmosphere.
- Studies examining ward-atmosphere in relation to the physical environment.
- Studies comparing different wards.
- Studies only examining the reliability and/or validity of instruments used to measure ward-atmosphere.
• Studies where the sample is made up of less than 50% of forensic mental health participants.
• Studies examining ward-atmosphere interventions
• Studies examining staff factors and their association with ward-atmosphere.

**Rating of Included Studies**

**Risk of Bias**

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) group (Moher, Liberati, Tetzlaff & Altman, 2009) suggest that assessing risk of bias is a more appropriate approach to systematically critiquing research as opposed to rating “quality” that has been used more commonly in the past. It has been suggested that numerical ratings or “scores” of quality are unhelpful and misleading and that risk of bias categories of high, low and unclear may be more useful (Moher et al., 2009; Higgins & Altman, 2008; Greenland & O’Rourke, 2001). Sanderson, Tatt and Higgins (2007) conducted a systematic review to examine tools for assessing quality and susceptibility to bias in observational epidemiological studies. While they did not recommend a specific tool, they recommended more broadly that “tools should (i) include a small number of key domains; (ii) be as specific as possible (with due consideration of the particular study design and topic area); (iii) be a simple checklist rather than a scale and (iv) show evidence of careful development, and of their validity and reliability” (Sanderson et al., 2007, pg 674). As suggested by Sanderson et al. (2007), a checklist for use in observational studies in epidemiology was adopted to systematically assess risk of bias in this review. See Appendix 2 for further details of the risk of bias tool domains. Inter-rater agreement was high for all papers (89%) and any disagreements were resolved by discussion.
Results

Selection process

The PRISMA flow diagram of the study selection process (The PRISMA Group, Moher et al., 2009) provides a summary of the process utilized to select the studies included in this review (See Figure 1). Five hundred and seventy two potential papers were identified through the electronic search, a further 3 studies were identified via hand searches of the reference lists of key articles, giving a total of 575 studies. Of these, 286 duplicates were extracted using a manual hand search. A further 249 were excluded following a review of the article abstracts. Following this, full text articles were assessed of the 40 remaining papers. These articles were independently reviewed by two researchers (F.S and A.G) for eligibility using the criteria outlined above. Any disagreements were resolved through discussion. Of these 32 were excluded for the following reasons: study examined the physical ward environment (n=13), study examined perceptions of ward-atmosphere (n=4), study examined cross sectional ward comparisons (n=3), study examined validity of ward-atmosphere measures (n=6), study did not measure ward-atmosphere (n=1), study examined interventions to address ward-atmosphere (n=4), study sample contained less than 50 per cent forensic patients (n=1), A hand search of the reference list of the 8 identified studies found no additional papers.
Figure 1. PRISMA (2009) Flowchart of the article selection process

Records identified through database searching (n = 572)

Additional records identified through other sources (n = 3)

Total (n = 575)

Records after duplicates removed (n = 289)

Records screened (n = 289) → Records excluded (n = 249)

Full-text articles assessed for eligibility (n = 40)

Full-text articles excluded, with reasons (n = 32)
  Physical (n=13)
  Perceptions of ward-atmosphere (n=4)
  Compared different wards (n=3)
  Measures of ward-atmosphere validity/reliability studies (n=6)
  No measure of ward-atmosphere (n=1)
  Ward-atmosphere intervention (n=4)
  Sample contained <50% forensic participants (n=1)

Studies included (n = 8)
Included Studies

Eight studies were identified for inclusion in the review (Beazley & Gudjonsson, 2011; Bressington, Stewart, Beer & McInnes, 2011; Campbell, Allan & Sims, 2014; Dickens, Suesse, Synman & Picchioni, 2014; de Vries, Brazil, Tonkin & Bulten, 2016; Livingston, Nijdam-Jones & Brink, 2012; Long et al., 2011; Ros, Van der Helm, Wissink, Stams & Shaftenaar, 2013).

What are the characteristics of the studies which examine ward-atmosphere in forensic mental health settings?

Study/Participant Characteristics

Table 1 provides a summary of the studies that examined service user factors associated with ward-atmosphere. Five hundred and sixty four participants were included in the eight studies. Of these, 367 (65%) were male and 125 (22%) were female. Ros et al. (2013) did not report data on the gender of their participants (n= 72, 13%). Using the information that was reported, the mean age of participants was 35.74 years, range (30.5- 40). Studies recruited participants from open (Dickens et al., 2014), low (Dickens et al., 2014; Bressington et al., 2011; Livingston et al., 2012; Long et al., 2011), medium (Beazley & Gudjonsson 2011; Bressington et al., 2011; Campbell et al., 2014; Dickens et al., 2014; Livingston et al., 2012; Long et al., 2011) and high ( de Vries et al., 2016; Livingston et al., 2012) secure settings. One study (Ros et al., 2013) described the setting as a “forensic mental health unit and secure clinic”. Diagnoses included psychosis (n=200, 35%, including schizophrenia, schizoaffective, bipolar, psychotic illness and other psychosis), personality disorder (n=81, 14 %), others (n=15, 3 %, including PTSD/Affective/Anxiety/Substance misuse), Developmental Disorder (n=7, 1.2 %) and unknown/missing data (n=272, 47%). Three studies reported on mean length of stay on the
ward (Campbell et al., 2014, DeVries et al., 2016; Livingston et al., 2012) with this being 30.66 months. Bressington et al. (2011) reported that modal length of stay was more than 24 months.
Table 1. Characteristics of included studies

<table>
<thead>
<tr>
<th>Author/Year</th>
<th>Aim</th>
<th>Design and Sample Characteristics</th>
<th>Measures</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| Beazley and Gudjonsson (2011) | To examine the relationship of depression and ward-atmosphere in influencing motivation | Cross sectional                  | Consent rate, Attrition Rate, Rate of Follow Up | Depressed patients were more likely to report a poor ward-atmosphere ($r = -0.41$, $p < 0.05$)  
Those who showed poor levels of motivation also reported poor ward-atmosphere ($r = 0.3$, $p < 0.05$).  
Depression was found to predict motivation in a model mediated by ward-atmosphere and ward-atmosphere predicted motivation in a model mediated by depression |
|                      | Data collected from a Medium secure unit.  
Inpatients (N=60)  
83.3% Male  
16.7% Female  
80% Schizophrenia-spectrum disorder  
38% - Personality Disorder | 89 patients on the unit.  
12 = too unwell  
17 declined  
60 participated | Patient Motivation Inventory (PMI)  
Ward Atmosphere Scale (WAS)  
Centre for Epidemiological Studies Depression Scale (CES-D) |                                                                 |
| Bressington et al. (2011) | To examine levels of service user satisfaction and its relationship with ward- | Cross Sectional                  |                                                      | Patient ratings of ward-atmosphere were found to have a significant positive correlation with satisfaction with forensic services ($r_{range} = 0.34 - 0.71$). |
|                      | Data collected from 4 medium secure and 3 low secure units. | 45 out of 110 consented  
1 defaced paperwork | Forensic Satisfaction Scale (FSS)  
Social Climate in Forensic Settings (EssenCES) |                                                                 |
<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Design</th>
<th>Participants</th>
<th>Measures</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campbell et al. (2014)</td>
<td>To examine whether inpatient perceptions of ward-atmosphere have more influence on their attachment to a service than their own attachment styles.</td>
<td>Cross sectional</td>
<td>N= 76 Male Inpatients Diagnosis of a psychotic illness Mean age= 35.5 years Mean duration of stay= 16.68 months</td>
<td>Service attachment Questionnaire (SAQ), The Psychosis Attachment Measure (PAM), Social climate for Forensic Settings (EssenCES), The Positive and Negative Affect Schedule (PANAS)</td>
<td>Of 107 eligible, 31 refused to take part. Significant positive correlations were found between service attachment and perceptions of ward-atmosphere (r range= 0.30-0.72, p &lt; 0.01) A significant negative correlation was found between perceptions of ward-atmosphere and attachment avoidance (r= -0.25, p &lt; 0.001). Attachment avoidance and perception of ward-atmosphere explained 21% of the variance in service attachment after controlling for negative affect [ R² change = 0.21, F change (3,72) = 16.19, p &lt; 0.001] Ward-atmosphere (β=0.47, p &lt; 0.001) and negative affect (β=0.41, p &lt; 0.001) were independently associated with service attachment.</td>
</tr>
<tr>
<td>de Vries et al. (2016)</td>
<td>To provide more insight</td>
<td>Cross sectional</td>
<td>Social climate for Forensic Settings</td>
<td>Ward-atmosphere was found to be significantly negatively associated with the</td>
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</tbody>
</table>
into the relationship between patient characteristics and perceived ward-atmosphere.

Data collected from a High secure forensic psychiatric institution.
N=154 patients
100% Male
Patients:
All with Axis I or II diagnosis.
Mean age = 39.25 years
Mean length of stay = 29.2 months

Dickens et al. (2014)
To explore whether and how patient’s demographic and clinical characteristics are associated with the ward-atmosphere.

Cross sectional
Inpatients in a secure forensic mental health service
N=63
44% Male
56% Female
Diagnosis
Psychotic spectrum =51%

89 referred, 63 consented.

Social Climate in Forensic Settings (EssenCES)
Risk (HCR-20)
Diagnosis (Clinical team use of ICD-10)
Current clinical presentation (Clinical items of the HCR-20)
Risk- related incidents-

antisocial facet of the PCL-R (β = -0.32, p< 0.05), the clinical facet of the HCR-20 (β= -0.34, p< 0.05).

Ward-atmosphere was found to be significantly positively associated with the historical facet of the HCR-20 (β_{range}=0.30-0.33, p < 0.05), and the interpersonal facet of the PCL-R (β = 0.23, p < 0.05)

No significant associations were found between ward-atmosphere and length of stay, the affective facet of the PCL-R, the lifestyle facet of the PCL-R, the risk facet of the HCR-20

The number of risk related incidents, as well as the ‘Clinical’ facet of the HCR-20 sub-
| Livingston et al. (2012) | To examine patient centred care from the perspectives of patients and providers in a forensic mental health hospital. | Personality Disorder = 35%  
Developmental Disorder = 11%  
Affective disorder = <2%  
Anxiety disorder = <2%  
Level of security- Open= 5%  
Low = 62%  
Medium = 33% | Overt Aggression Scale (OAS)  
Treatment engagement (count of therapeutic sessions)  
Current leave status | scale scores failed to explain a significant portion of the variation in ward-atmosphere. | Cross sectional 190 bed forensic hospital (high, medium and low security levels)  
Patients  
N = 30  
80% male  
20% female  
Mean age = 40 years  
Self reported diagnoses-  
Recovery oriented care-Recovery Self assessment scale (RSA): Patient version  
Social Climate in Forensic Settings (EssenCES)  
Personal Recovery-The Mental Health Recovery Measure(MHRM)  
Engagement- Singh | Patient ratings of recovery oriented care were positively correlated with ward-atmosphere (r range= 0.52 - 0.66, p < 0.01)  
No associations were found between ward-atmosphere and personal recovery, empowerment, engagement and internalised stigma. |
| Long et al. (2011) | To assess the ward-atmosphere in a women’s secure wards and its variation by level of security and ward type, therapeutic alliance, patient motivation, treatment engagement and disturbed | Cross sectional | Social Climate in Forensic Settings (EssenCES) | Social Climate in Forensic Settings (EssenCES) was found to be significantly positively correlated with motivation ($r_{range} = 0.26-0.54, p < 0.05$), therapeutic alliance ($r_{range} = 0.16-0.59, p < 0.01$), session attendance ($r=0.25, p < 0.05$), number of programmed sessions attended ($r_{range}=0.23-0.25, p< 0.01$), level of security ($r_{range}=0.25-0.29, p< 0.01$), behavioural disturbance and seclusions ($r_{range} = 0.24-0.50, p < 0.05$). Therapeutic alliance independently predicted total ward-atmosphere ratings accounting for 37% of the total variance of the model ($\beta=0.69, p < 0.05$). |
| Schizophrenia= 60%, schizoaffective disorder= 17%, bipolar disorder= 10%, other psychotic= 7%, unknown = 7% | O’Brien Level of Engagement Scale (SOLES) | O’Brien Level of Engagement Scale (SOLES) independently predicted total ward-atmosphere ratings accounting for 37% of the total variance of the model ($\beta=0.69, p < 0.05$). |
| 92% of patients participated | Empowerment- The Making Decisions Empowerment Scale | Empowerment- The Making Decisions Empowerment Scale |
| Patients N= 65 | Internalised stigma- Internalised stigma of Mental Illness Scale (ISMA) | Internalised stigma- Internalised stigma of Mental Illness Scale (ISMA) |
| Mean age= 32.5 years 100% Female | Social Climate in Forensic Settings (EssenCES) | Social Climate in Forensic Settings (EssenCES) |
| Secure hospital for women. 2 medium security wards, 2 low security wards. | Social Climate in Forensic Settings (EssenCES) | Social Climate in Forensic Settings (EssenCES) |
| Patient diagnosis- Personality disorder = 55%, Schizophrenia or schizoaffective | Social Climate in Forensic Settings (EssenCES) | Social Climate in Forensic Settings (EssenCES) |
| | Social Climate in Forensic Settings (EssenCES) | Social Climate in Forensic Settings (EssenCES) |
Ros et al. (2013) To examine the influence of ward-atmosphere on aggressive behaviour

| behaviour. disorder = 25%, PTSD, Bipolar and affective disorders, substance dependence= 20% 95% patients detained under the MH Act. form) Behavioural disturbance- Overt Aggression Scale (OAS), hospital’s own prevention and management of violence PMAV), the number of episodes of seclusion. | Ros et al. (2013) To examine the influence of ward-atmosphere on aggressive behaviour | Longitudinal Patients = 1 forensic mental health unit and 1 secure clinic for prolonged intensive care Patients N= 72 Mean age 36.7 years Respondents filled in an institutional climate questionnaire three times (T1, T2, and A total of 117 patients were admitted to the clinic. N = 74 (63.2%) filled in the questionnaires, with a non-response rate of N = 43 (36.8%). N=2 did not complete follow up questionnaires Social climate: Prison Group Climate Inventory– Short Form (PGCI-SF). Aggression: Frequency of Aggressive Incidents - Overt Aggression Scale (OAS). | Open group climate was found to be significantly negatively associated with aggression during Time 1 and Time 2 (r = −0.25, p < 0.05) and during Time 2 and Time 3 (r = −0.23, p < 0.05). Support and atmosphere at Time 1 were negatively associated with aggressive incidents during Time 1 and Time 2 (r = −0.25, p < 0.05, r = −0.24, p = < 0.05). No significant correlations were found between growth and repression at Time 1 and aggressive incidents during either timeframes. Atmosphere at Time 2 proved to be negatively associated with aggressive |
T3) with four and seven weeks in between, respectively. Incidents during Time 2 to Time 3 ($r = -0.24$, $p < 0.05$).

Structural equation modelling showed that the relation between growth and aggressive incidents at Time 1 was mediated by support (Indirect effect = 0.016, SE = 0.94, $p < 0.01$).
What service user factors are associated with ward-atmosphere in forensic mental health settings?

Throughout the eight studies a number of factors were investigated and these can be separated into the domains of service user characteristics and relational / process factors. The details of the different associations are displayed in Table 2.

Table 2. Factors found to be associated with ward-atmosphere

<table>
<thead>
<tr>
<th>Domain</th>
<th>Relationship</th>
<th>Factor</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service User Characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical</td>
<td>Positive</td>
<td>Personality Disorder, Psychosis</td>
<td>(β=1.41)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Satisfaction, Motivation</td>
<td>(β=0.99)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(r\text{range}=0.34-0.71)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>(r\text{range}=0.26-0.54)</td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td>Attachment Avoidance, Depression</td>
<td>(r=-0.25)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(r=-0.41)</td>
</tr>
<tr>
<td>Risk</td>
<td>Positive</td>
<td>Historical Risk, Interpersonal</td>
<td>(β\text{range}=0.30-0.33)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problems</td>
<td>(β=0.23)</td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td>Overall Risk, Current Risk,</td>
<td>(β=-0.16)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Antisocial Behaviour</td>
<td>(β=-0.34)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(β=-0.32)</td>
</tr>
<tr>
<td></td>
<td>Inconsistent</td>
<td>Aggression</td>
<td>(r\text{range}=-0.23 - -0.25) / (r\text{range}=0.24-0.50)</td>
</tr>
<tr>
<td>Relational/Process</td>
<td>Positive</td>
<td>Therapeutic Alliance, Recovery</td>
<td>(r\text{range}=0.16-0.59)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Oriented Care, Service Attachment</td>
<td>(r\text{range}=0.52-0.66)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(r\text{range}=0.30-0.72)</td>
</tr>
<tr>
<td></td>
<td>Negative</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inconsistent</td>
<td>Treatment Engagement</td>
<td>(β=-0.10) / (r=0.25)</td>
</tr>
</tbody>
</table>

When considering clinical factors, the findings suggest that a diagnosis of personality disorder or psychosis and higher levels of motivation and satisfaction, are associated with a more positive perception of ward-atmosphere, whereas higher levels of attachment avoidance and depression are associated with a poorer perception of ward-atmosphere.
In relation to risk factors, the results indicate that those with higher levels of historical risk and those with more interpersonal problems have a more positive perception of ward-atmosphere and those with higher overall and current levels of risk as well as those with more antisocial behaviour have less positive perceptions of ward-atmosphere. Two studies investigated the relationship between aggression and ward-atmosphere. Interestingly, the findings were inconsistent with Ros et al. (2013) finding significant negative correlations and Long et al. (2011) finding significant positive correlations. It is therefore difficult to draw firm conclusions regarding aggression.

In terms of the relational / process factors, more positive perceptions of the ward were associated with greater perceptions of recovery oriented care as well as greater therapeutic alliance and service attachment. Two studies also examined the association between ward-atmosphere and treatment engagement. Again, there were inconsistent and somewhat surprising results, with Dickens et al. (2014) finding negative associations and Long et al. (2011) finding positive associations. This is clearly an area that requires further investigation.

**Multivariate Analyses**

Beazley and Gudjonsson (2011), Long et al. (2011) and Campbell et al. (2014) conducted more robust multivariate analyses, in addition to bivariate correlations. Long et al. (2011) found that six factors (motivation; therapeutic alliance; treatment engagement; level of security; number of risk behaviours; behavioural disturbance) predicted 52.6% of the variance in ward-atmosphere ($R^2=0.0526$, $F(7,8)=1.26$, $p < 0.05$) and that therapeutic alliance independently predicted total ward-atmosphere ratings accounting for 37% of the total variance of the model ($\beta=0.69$, $p < 0.05$).
Campbell et al. (2014) reported that ward-atmosphere and attachment avoidance explained 21% of the variance in service attachment after controlling for negative affect [ \( R^2 \text{ change} = 0.21, F \text{ change} .(3,72)=16.19, p < 0.001 \)]. Further to this they found that both ward-atmosphere (\( \beta=0.47, p<0.001 \) and negative affect (\( \beta=0.41, p<0.001 \)) were, independently associated with service attachment.

Beazley and Gudjonsson (2011) found that there was a bi-directional relationship between depression, ward-atmosphere and motivation. They suggested that depression not only influences the perceptions of the ward, but a poor ward can increase symptoms of depression. Further to this, they explained that the nature of this relationship meant that depression affects motivation through ward-atmosphere, and ward-atmosphere affects motivation through depression.

**What methodological features are associated with increased risk of bias?**

Table 3 provides details of the risk of bias ratings for each of the included studies. Only one study (Dickens et al., 2014) was rated as having an overall low risk of bias. It is important that these are taken into account when considering the results of the studies and as such, findings must be interpreted with caution. A detailed breakdown of the risk of bias ratings can be found in Appendix 3.

**Methods for selecting study participants**

The majority of studies had small samples sizes putting them in danger of making their samples unrepresentative, with an over representation of more complaint or engaged participants. The studies also suffer from selection bias, whereby those who were more unwell may not have been included (Dickens et al., 2014; Livingston et al., 2012; Beazley & Gudjonsson 2011; Campbell et al, 2014; Bressington et al., 2011; Ros et al., 2013).

While considering the representativeness of a sample, it is also important to know about its
key characteristics. De Vries et al. (2016), Long et al. (2011) and Ros et al. (2013) provided no detail of inclusion and exclusion criteria. DeVries et al. (2016) and Ros et al. (2013) did not provide details of the demographic or diagnostic characteristics of their samples. The study by Ros et al. (2013) was not particularly representative having recruited from just two wards within one hospital.

Methods for measuring exposure and outcome variables
The methods for measuring ward-atmosphere and the other variables under investigation were well described and appeared to be appropriate in all studies.

Methods to control confounding variables
It is important to consider what factors, other than the ones under investigation, may influence ward-atmosphere. Common variables include the age and gender of patients. However when considering ward-atmosphere, other factors including diagnosis, symptom severity, mood, contact with nursing staff and length of time on the ward may also confound the statistical associations drawn. In forensic settings, the level of security may also be important to consider. In the current review, only a small number of studies made adequate attempts to control for confounding variables (Dickens et al., 2014; Campbell et al., 2014; de Vries et al., 2016; Ros et al., 2013)

Statistical Methods
Sample Size Determination
One area that appeared to be particularly neglected within the included studies was in relation to sample size and its determination. Only one study, Dickens et al. (2014) gave a detailed description of the power analysis with associated effect size, significance level and
sample size. Beazley and Gudjonsson (2011) while providing less detail did acknowledge the issue of power within their model and adjust their sample accordingly.

Consideration of assumptions of tests and multiple testing
An area that was rarely addressed related to whether or not assumptions of the statistical tests were met and whether adjustments had been made for multiple testing. Dickens et al. (2014) and Campbell et al. (2014) were the only studies that addressed these issues fully.

Consideration of clustering of data
The nature of the data within the included studies can be regarded as clustered or hierarchical data. Although each individual provides their own score, those residing or working within a particular ward will inevitably be more similar in certain characteristics than those who are not working or residing together. None of the included studies made reference to or controlled for the problem of clustering of data and the possible consequences of this upon their analyses.
Table 3. Risk of Bias for studies examining factors associated with ward-atmosphere

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods for selecting study participants</th>
<th>Methods for measuring exposure and outcome variables</th>
<th>Methods to control confounding</th>
<th>Statistical methods (excluding control of confounding) -Sample size determination</th>
<th>Statistical methods (excluding control of confounding) -Assumptions of tests</th>
<th>Statistical methods (excluding control of confounding) -Multiple testing</th>
<th>Statistical methods (excluding control of confounding) -Clustering</th>
<th>Overall Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beazley and Gudjonsson (2011)</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>UNCLEAR</td>
<td>UNCLEAR</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>Bressington et al. (2011)</td>
<td>HIGH</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>Campbell et al. (2014)</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>de Vries et al. (2016)</td>
<td>UNCLEAR</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>N/A</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>Dickens et al. (2014)</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>HIGH</td>
<td>LOW</td>
</tr>
<tr>
<td>Livingston et al. (2012)</td>
<td>HIGH</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>Long et al. (2011)</td>
<td>LOW</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>UNCLEAR</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
<tr>
<td>Ros et al (2013)</td>
<td>HIGH</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
</tr>
</tbody>
</table>
Discussion

This paper aimed to identify, synthesise and discuss key factors associated with ward-atmosphere in forensic mental health settings. It also aimed to critically analyse the research in this area. To the author’s knowledge there has been no previous systematic review in this area with much of the focus having been on non-forensic settings. Eight studies were identified and the findings suggest that there are a number of service user factors associated with ward-atmosphere. Factors were found to relate to service user characteristics (clinical and risk factors) and relational / process variables. When considering clinical factors it was found that diagnosis of personality disorder or psychosis and higher levels of motivation and satisfaction, were associated with more positive perceptions of ward-atmosphere. While higher levels of attachment avoidance and depression correlated with poorer perceptions of ward-atmosphere. In terms of risk factors, it was found that those with higher levels of historical risk and those with more interpersonal problems had a more positive perception of ward-atmosphere. Those with higher overall and current levels of risk as well those with more antisocial behaviour were found to have less positive perceptions of ward-atmosphere. There were inconsistent findings regarding the relationship between ward-atmosphere and aggression. A number of relational / process factors were also investigated and the findings indicated that more positive perceptions of the ward were associated with greater perceptions of recovery oriented care as well as greater therapeutic alliance and service attachment. Inconsistent results were found when considering the associations between ward-atmosphere and treatment engagement.

It is however important to consider the methodological limitations of the research when interpreting the results. All but one of the included studies was found to have a high risk of bias. Studies often recruited small samples, with little consideration of power, the
effects of multiple testing and the influence of data clustering. The majority of the studies were cross sectional in design and there was little explanation or justification as to why particular variables had been chosen for investigation. These issues may go some way to explaining some of the inconsistent findings within the data. The vast range of variables, lack of theoretical coherence and the high risk of bias in the studies make the synthesis of findings challenging. However, one approach that may assist in the integration and application of the findings is to consider a diagrammatic implementation model (Figure 2).

*Implementation Model*

The model shows that by considering the service user characteristics (clinical and risk) as well and the relational / process factors that have been identified as being associated with ward-atmosphere in the current study, specific activities/ inputs and areas for future intervention can be developed that target these areas. It is hoped that these activities would lead to more positive perceptions of ward-atmosphere and in turn, more positive outcomes for service users. The model also shows what inputs are required to facilitate the proposed activities and interventions.
Figure 2. Implementation model of factors associated with ward-atmosphere in forensic mental health settings

Service User Characteristics
Clinical:
- Personality Disorder
- Psychosis
- Depression
- Attachment avoidance
- Motivation
- Satisfaction
Risk:
- Antisocial behaviour
- Interpersonal problems
- Aggression

Activities/Interventions
- Increased Support
- Recovery Focus
- Focus on Therapeutic Alliance: Bond: Goals: Task
- Focus on attachment: Safe Haven – Expressing distress
- Secure Base: Autonomy
- Focus on emotional experiences
- Balancing Security with Autonomy

Inputs
- Staff Training
- Staff Support
- Staff Supervision
- Skills Training
- Reflective Practice Groups

Ward-Atmosphere

Outcomes
Improved:
- Mood
- Therapeutic alliance
- Increased levels of:
- Satisfaction
- Motivation
- Treatment engagement
- Service attachment
- Recovery oriented care
Reduced:
- Aggression
- Antisocial behaviour
- Interpersonal problems
Clinical Implications of the Model

Having activities and approaches that can target the service user characteristics that are associated with ward-atmosphere may go some way to improving outcomes. It will therefore be important that services have a strong recovery focus as well as a commitment to improved support for service users (responsive staff who value trust and respect). Activities and interventions should have a focus on the therapeutic alliance as well as the emotional experiences of service users. It will be important that services focus on attachment whereby service users can experience the ward as a safe haven, where they can express distress but also as a secure base that promotes autonomy. The idea of balancing security with autonomy will be of particular importance within forensic settings. It is imperative that measures and processes are put in place to facilitate the application of this model. In practice, this will require a whole systems approach and could include, among many things, staff training, support, supervision and reflective practice groups.

Clinical Implications of the Current Study.

Given the significance of the interpersonal environment in the course of severe mental ill health and recovery, systemic interventions that consider the contribution of the staff team and can target ward-atmosphere have the potential to make a significant difference in the quality of life of those residing within hospital. Having a better knowledge of the correlates of ward-atmosphere can develop our understanding of how it can be managed or changed, in order to ensure that service users have an effective therapeutic environment that can facilitate wellbeing and recovery.

Research Implications

Further research is required to replicate the findings in the included studies. While many factors were investigated, there was very little overlap in what each of the studies
examined and as such little opportunity to see consistent patterns of findings. Future studies would be improved through comparison of similar variables, larger sample sizes and longitudinal designs rather than cross sectional designs, where causality can be more easily identified. In addition to this, it is crucial that inherent methodological limitations identified within this study are addressed.

Further investigation of the more dynamic/interpersonal factors associated with ward-atmosphere would be particularly beneficial as these are more amenable to change through intervention. While it is useful to identify the correlates of ward-atmosphere it would also be useful to gain a better understanding of the mechanisms underlying the associations with ward-atmosphere. Again, this would facilitate effective management and development of interventions or staff training to improve ward-atmosphere. Much of the work has concentrated on service user factors however further research should aim to investigate staff factors in more detail.

**Limitations**

Several limitations of this review should be considered when interpreting its findings. Despite that every attempt was made to produce an exhaustive account of all of the relevant research on the topic, there is a possibility that some studies may have been missed. Added to this, there was no measure of inter-rater reliability at the abstract screening stage. While beyond the scope of this project, normal practice would be that more than one person would review all of the titles and abstracts of search results. This improves reliability but also reduces the chance for human errors. Unpublished studies were excluded from the review and it is important to consider that this which will have introduced publication bias. Other limitations of this review are related to the features of the individual studies. It was difficult to draw comparisons between studies due to the variation in the factors that were being examined as well as how these factors were measured and defined.
Conclusions

This was the first review to synthesise the research examining the factors associated with ward-atmosphere in forensic mental health settings. Overall, a number of factors were investigated and found to have significant associations with ward-atmosphere, however a number of contradictory findings were also evident. Studies were conducted in a variety of settings with varying populations and there were a number of methodological issues which increased the risk of bias within the included studies. Further replication with a smaller variation in factors under investigation would help to clarify the most pertinent associations. Closer inspection of factors that may be more amenable to change could help to facilitate the development of targeted intervention to improve staff and service user experiences.
References

*References marked with an asterisk indicate studies included in the systematic review.


CHAPTER TWO
MAJOR RESEARCH PROJECT

“At the end of the day he’s still my son”: An Interpretative Phenomenological Analysis of mothers’ experiences of having a son in Forensic Mental Health Services.

Fiona Scott*

Declaration of interests: None

Word count (including abstract, quotes and references): 9248

Written according to guidelines for submission to The Journal of Forensic Psychiatry and Psychology
(See Appendix 1 for a summary of author instructions).

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Submitted in partial fulfilment of the requirement for the degree of Doctorate in Clinical Psychology (DClinPsy)
Abstract

**Background:** People using forensic mental health services often have complex difficulties and the impact of these on carers is an area requiring further investigation. Little is known about the experiences of caregiving in the context of forensic mental health services.

**Aims:** This study aimed to investigate the experiences of caregiving from the perspective of mothers of patients receiving forensic mental health services, specifically how they have made sense of their experiences, roles and relationships.

**Methods:** The study was designed following the principles of Interpretative Phenomenological Analysis (IPA). Five mothers provided their informed consent to participate in semi-structured interviews exploring their experiences of caregiving in a forensic context. Interviews were transcribed and analysed in line with IPA methodology.

**Results:** Four superordinate themes emerged from the data: 1) The process of coming to terms with what happened 2) Evolving relationships 3) Negotiating the conflict between vulnerability and threat 4) The emotional realities of being a mother.

**Applications:** Participants’ accounts provided valuable insights into the complex nature of caregiving within a forensic context but also highlighted implications for clinical practice, service provision and future research.
Plain English Summary

Title: “At the end of the day he’s still my son”: An Interpretative Phenomenological Analysis of mothers’ experiences of having a son in Forensic Mental Health Services.

Background: People using forensic mental health services often have complex difficulties. As well as understanding what this is like for service users, it is important to know more about what it is like for their carers. We know less about the impact of caregiving within forensic settings. It will be useful to gain a better understanding of carers’ experiences and perspectives as this will help to improve services and interventions for both carers and service users.

Aims: This study aimed to better understand what it’s like for mothers to have a son within forensic mental health services. In particular, if this has impacted upon how they saw their roles, relationships and experiences.

Methods: Interviews were undertaken with five mothers who had sons who were involved with forensic mental health services. The semi-structured interviews were audio recorded and then transcribed verbatim and analysed using interpretative phenomenological analysis.

Results: It was possible to group what the participants said into four main themes that related to their experiences of caring for their son: 1) The process of coming to terms with what happened 2) Evolving Relationships 3) Negotiating the conflict between vulnerability and threat 4) The emotional realities of being a mother.

Applications: Participants described a range of experiences and it is hoped that these findings can inform developments in service provision and the delivery of family interventions within forensic mental health services.
Introduction

Individuals seen by forensic mental health services often have complex difficulties, substantial service needs (Phipps, 1994), and a disproportionate number of mental health problems (Keene & Rodriguez, 2005). The prevalence of psychosis in individuals within the criminal justice system is estimated to be twenty times that of the general population (Joint Commissioning Panel for Mental Health, 2013). Carers of those with psychosis have been found to experience high levels of psychological distress, including anxiety and depression, economic strain, reduced quality of life and stigmatization (Martens & Addington, 2001; Scazufca, Kuipers & Menezes, 2001; Tennakoon et al., 2000; Treasure et al., 2001).

It is important to understand how families respond to their relatives’ experience of psychosis. Kuipers, Onwumere and Bebbington (2010) suggested that carer appraisals of service user illness and behaviour bring about cognitive and affective reactions which can in turn influence behaviours towards service users and services. These cognitive and affective responses are hypothesised to be in part based upon changes in their loved one’s behaviour but are also based on the qualities of the initial attachment relationship (Patterson, Birchwood and Cochrane, 2005). Bowlby (1969; 1980; 1988) as well as describing the attachment system, was first to describe the caregiving system. This was proposed as a system of organised behaviour shown by an attachment figure towards their child. It has been described as an evolved system, which is distinct from, but reciprocal to, the attachment system (Solomon and George, 1996), which functions to provide protection (Solomon and George, 1996; George and Solomon, 1996; George and Solomon, 2008). Under normal circumstances, threats activate the infant’s attachment system and they seek and move towards their attachment figure for protection. Similarly, when a caregiver
detects danger, the caregiving system is activated and they move towards the infant to provide protection (Solomon and George, 1996).

Much of the evidence concerning families’ and carers’ adaptations to a relative coping with psychosis have been derived from adult mental health settings (Barrowclough and Hooley, 2003; Grice et al., 2009; Raune, Kuipers & Bebbington, 2004; Barrowclough and Parle, 1997; Scazufca and Kuipers, 1999, Barrowclough, Lobban, Hatton, & Quinn, 2001, Kuipers et al., 2010). Carers of those within the forensic system have been found to take on a significant burden of care in this population (Tsang, Pearson & Yuen, 2002; James, 1996). They may face the additional challenge of responding not only to the occurrence of a psychosis but also an offence or series of offences committed by their loved one. There have been very few studies conducted specifically to investigate family carers’ experiences of caring for a relative supported within a forensic context (Ridley et al., 2014; Canning, O’Reilly, Wressell, Cannon & Walker, 2009; MacInnes, Beer, Reynolds & Kinane, 2013). Using grounded theory, Nordstrom, Kullgren and Dahlgren (2006) investigated parents’ experiences of caring for adult sons who were seen in forensic mental health services due to psychosis and a history of violent offending. Four key themes were constructed: onset of mental disorder, diagnosis of schizophrenia, violent behaviour/criminality and referral to forensic psychiatric treatment. These experiences were found to elicit emotional reactions such as guilt, fear, disappointment, anger and relief, which in return led to different responses including searching for causes, searching for information, staying ignorant, distancing, blaming others, hoping for the future and transferring responsibility. A review by Tsang et al., (2002) examined the needs and burdens of mentally ill offenders (James, 1996; McCann, 1993; McCann & McKeown, 1995; McCann, McKeown & Porter, 1996). They suggested that the relatives of offenders with mental illness experience more stress than those of service users who do not have an
offending history. They found that their relatives experienced additional stigma related to the criminal offence, and a need to cope with legal proceedings and concerns regarding violence.

There is a need for further research exploring the experiences of carers in a forensic context. Improving our understanding of caregiving in this context could help develop therapeutic approaches that have a more sensitive incorporation of caregiving experiences. The exploration of mothers’ experiences in particular was chosen as a point of departure given the traditional emphasis placed on the maternal relationship in the attachment and caregiving literature.

**Aim**

To investigate the experiences of caregiving from the perspective of mothers of patients receiving forensic mental health services, specifically how they have made sense of their experiences, roles and relationships.

**Method**

**Design**

This study utilised Interpretative Phenomenological Analysis (IPA). IPA explores how individuals make sense of their personal and social world, with a focus on finding the meanings that are attached to specific experiences (Smith & Osborn, 2008). IPA has roots in epistemology while also focussing upon 1) phenomenology, a philosophical approach concerned with lived experience 2) double hermeneutics, whereby the researcher attempts to make sense of the individual who is making sense of their own experiences 3) idiographic in-depth exploration of individual cases (Smith, Flowers & Larkin, 2009). In accordance with IPA methodology, purposive homogeneous sampling was utilised such
that participants were selected due to their experiences of caregiving and the in depth insight they can provide into these experiences.

**Participants**

Participants were English speaking mothers of patients in forensic mental health services in contact with NHS Lanarkshire or mothers in contact with Support in Mind Scotland. Potential participants were excluded if they had active psychotic symptoms, had known health and safety risks placing the researcher at risk or were no longer in contact with the associated family member. Seven potential participants who met inclusion criteria were identified. One individual attending the NHS Lanarkshire’s forensic carers group decided against taking part, as did one person who was approached by a staff member individually. It is not known why they did not wish to participate. No participants were identified through Support in Mind Scotland. Five individuals gave their informed and written consent to participate in the current study. This is within the recommended sample of between four and ten participants for Doctoral research studies employing IPA (Smith et al., 2009). Braun and Clarke (2013) have suggested that sample sizes should be adequate to ensure there is enough data to develop a rich story yet not too much that time and resources limit a deeper analysis of the data. Similarly, Smith et al., (2009) highlight that sample size is contextual in IPA and must be considered on a study by study basis. In this context, one might argue that mothers who have sons supported by forensic mental health services are a small but important group with which to consider. Hefferon and Gil-Rodriguez (2011) have said that given the idiographic focus in IPA, “less is more” in terms of sample size and that fewer participants examined at a greater depth is always preferable to a broader, shallow and simply descriptive analysis of many individuals.

Participants were aged between 52 and 70 years of age and they all had a son utilising forensic mental health services. Two of the sons were currently living in the community.
and three were inpatients in a low secure hospital. Pseudonyms were assigned to maintain anonymity. A summary of participant characteristics is shown in Table 1 below.
Table 1. Participant Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Judith</th>
<th>Claire</th>
<th>Maria</th>
<th>Anne</th>
<th>Susan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>67</td>
<td>59</td>
<td>52</td>
<td>70</td>
<td>60</td>
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<tr>
<td>Ethnicity</td>
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<td>White Scottish</td>
<td>White British</td>
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<td>Years since relative became unwell</td>
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<td>12</td>
<td>2.5</td>
<td>30</td>
<td>17</td>
</tr>
<tr>
<td>Years relative involved with forensic services</td>
<td>5</td>
<td>12</td>
<td>2.5</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Gender of relative</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Relatives’ Diagnosis (as described by mother)</td>
<td>Schizophrenia</td>
<td>Paranoid Schizophrenia</td>
<td>Drug induced psychosis/ Schizophrenia</td>
<td>Unsure Bipolar/Schizophrenia</td>
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</table>
Procedure

Prior to commencing recruitment, ethical approval was obtained from the West of Scotland Research Ethics Committee (Appendix 4) and Research and Development Management Approval was obtained for NHS Lanarkshire (Appendix 5). Recruitment took place between January and April, 2017. Participants were informed about the study via carer groups and staff of NHS Lanarkshire’s Forensic Mental Health Service, as well as Support in Mind Scotland. Staff were given information about the study (Appendix 7) and recruitment posters were placed in forensic mental health service venues (Appendix 8). Staff were encouraged to identify suitable participants and provide them with the Participant Information Sheet (PIS) (Appendix 6). In addition, with permission the researcher visited the NHS Lanarkshire forensic carers group and delivered a short presentation about the study. The PIS containing the contact details of the researcher was left for those interested in finding out more about the study. Those interested were asked to provide contact details to a staff member which were then returned to the researcher. The researcher then contacted the person to answer any questions and establish if they wished to participate. Following this, an interview was arranged for those who agreed to participate. Written informed consent was obtained prior to commencing the interviews (Appendix 9). Interviews were held in clinic rooms of local NHS venues.

Interviews

Interviews were semi structured (Appendix 10) and were conducted in a flexible, supportive, engaging manner, using open ended questions with further probes in a way that enabled the participant to explore and reflect on their experiences. The content of the semi structured interview was developed in collaboration with forensic carers from Support in Mind Scotland. Given their relevant insights and experiences, they were able to give
feedback as to the appropriateness and acceptability of the interview schedule. Due the sensitive and emotive nature of the interview topic, the researcher was aware that some individuals may become upset when discussing their experiences. Participants were assured that they did not have to answer any questions they were unwilling to and that they could take a break from interview if necessary. Participants were asked if they wished to be contacted by the researcher one week following the interview to discuss any concerns or ask questions they may have had about the interview process; however, none of the participants made such requests. The length of interviews ranged between 45 minutes and 65 minutes (average 60 minutes). All interviews were recorded before being transcribed verbatim and anonymised by the researcher, with identifying information removed.

**Data Analysis**

IPA was used to analyse the transcripts, following a number of recognised stages (Smith et al., 2009). Firstly, each transcript was read repeatedly, allowing the researcher to immerse herself and become familiar with the account. Next, exploratory descriptive, linguistic and conceptual codes were made on the right hand margin of the transcript (Appendix 11). Emergent themes were then developed on the left hand side of the transcript by identifying any patterns between these exploratory codes. Connections and patterns across the emergent themes were then identified within the transcript (Idiography). This process was repeated for each transcript. Once themes had been identified in individual transcripts, overarching superordinate and subordinate themes were identified across all transcripts by considering patterns, similarities and differences between accounts. A Microsoft Word document was created to record excerpts from the transcripts related to each emergent theme. An example of one of these documents can be found in Appendix 12. To investigate the validity of the themes identified, a secondary rater (research supervisor) independently
rated a sample of the transcripts. Discussion of emergent themes identified a good level of concordance.

**Researcher Reflexivity**

The researcher has a central role in the process of IPA. In particular, it is important to consider how the researcher’s beliefs, assumptions and experiences may influence the interpretation of the participant’s account. In order to increase awareness of potential sources of bias and the emotional reactions evoked by interview content, the researcher completed a reflective log. This enabled the process of ‘bracketing’ perspectives, ideas and expectations throughout the research process (Smith et al., 2009). Supervision was also used as a space to reflect on the emotional impact of the interviews and to facilitate the awareness of possible assumptions or sources of bias. Toma (2000) recommends attempting to get as close to the participant’s experience as possible in order to enhance understanding of this experience. As a forensically aligned Trainee Clinical Psychologist the researcher undertook a placement within the Forensic Mental Health Team within which the research was conducted. This gave the researcher an opportunity to become familiar with the forensic mental health context in Scotland. The researcher was able to gain knowledge and insight into the staff, service users and carers as well as the systems, processes and procedures that surround them. The researcher was able to reflect on these factors prior to and during the analysis process in order to maintain a balanced and open-minded approach.
Results

Four superordinate themes with associated sub themes emerged from the transcripts (Table 2).

**Table 2. Superordinate and Sub Themes**

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Sub Themes</th>
</tr>
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<tbody>
<tr>
<td>The process of coming to terms with what happened</td>
<td>“I knew he wasn’t well” - Index offence</td>
</tr>
<tr>
<td></td>
<td>“That left a scar” - Past Experiences</td>
</tr>
<tr>
<td></td>
<td>“Where did it go wrong” - Searching for answers and questioning</td>
</tr>
<tr>
<td>Evolving Relationships</td>
<td>“It’s like you’re losing him in a sense” - Loss and Change</td>
</tr>
<tr>
<td></td>
<td>“At the end of the day he’s still my son” - Acceptance</td>
</tr>
<tr>
<td>Negotiating the conflict between vulnerability and threat</td>
<td>“You either see it through or you walk away” - Ambivalence</td>
</tr>
<tr>
<td></td>
<td>“I feared for his life” - Son as vulnerable</td>
</tr>
<tr>
<td></td>
<td>“You dreaded him coming in” - Son as a threat</td>
</tr>
<tr>
<td>The emotional realities of being a mother</td>
<td>“My nerves were shattered” - Emotional/Physical Impact</td>
</tr>
<tr>
<td></td>
<td>“I was mortified” – Stigma</td>
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These themes essentially represent how participants perceived and understood their experiences of caregiving. Extracts from individual participants accounts have been selected to provide supporting evidence for each theme. In cases where subthemes applied differently to participants, divergent experiences are discussed.

**The process of coming to terms with what happened**

Throughout the interviews, it became clear that all five mothers had attempted to come to terms with what had happened with their sons. This process appeared to involve the mothers trying to understand and make sense of their experiences.
“I knew he wasn’t well” - Index offence

All five mothers had gone through a process of making sense of their son’s offending behaviour or index offence. Judith described her experiences when her son was in court:

*Judith*: “And even when they took him to court. He says, but I’ve not done anything, I’m not guilty, I’ve not done anything, because he didn’t know he’d done it”

*Interviewer*: “What do you think about that? What’s your take on that?”

*Judith*: “I knew he wasn’t well. I said to the police, I said, he’s sick, he’s no well” (Judith, pg 14)

Maria described her beliefs about her son’s index offence.

“........but I do believe that obviously he was insane at this point. He was insane he was not in his right mind.....Insanity brought on by drug abuse.....You know he’s been oot, he’s been wandering about you know, ducking and diving with the police. Just taking more drugs and just burying his head in the sand. And to the point where it’s just escalated and then he’s for some reason, I don’t know where he got the gun and he’s done that” (Maria, pg 19)

Susan describes how she had come to terms with what had happened on the night of her son’s index offence:

“I just thought, he must have been so ill, you know, so ill and [husband] would probably be noxious or whatever. I don’t, you don’t know what their last words were or whether” (Susan, pg 17)
“That left a scar” - Past experiences

All five mothers appeared to have engaged in a process of reflection to try and come to an understanding of past experiences and the influence these may have had on their son’s behaviours and/or difficulties. Judith explained what she understood to be one of the key incidents in her son’s early life and how this impacted upon him as he became unwell. Judith’s son had experienced a serious medical condition as a teenager, however he felt as though no one had believed that he had such a condition at the time:

“And that left a scar with [son] because he started to feel nobody believed him, didn’t matter what he did. So he just said well I’ll just thingwy because nobody believes me anyway, that’s the attitude he took” (Judith, pg 4).

Claire appeared to understand her son’s difficulties in the context of his shy, quiet personality:

Claire: “He was drinking alot and eh he got into a couple of fights and things like that. {okay, okay} He gets quite cheeky when he’s got a drink in him.{right} Ye. [son] has always been a quiet boy. I think he finds it hard to socialise {ah okay} And the drinking brought him out {I see} Confidence, you know. That’s why he liked to drink.” (Claire, pg 3)

Anne reflected on her son’s early experiences within the family environment and how she believed these have impacted upon him:

Interviewer: “Ok, so I wonder if you can tell me a wee bit about, when he first became unwell?”

Anne: “Well, he was always a handful. And as I say, the father wasnae there most of the time so it was the rules I made and then the father would come in and break them {ah, okay} So, [son] learnt from a very young age that he could manipulate us all.” (Anne, pg4)
“Where did it go wrong” - Searching for answers and questioning

Within the interviews, all five of the mother’s described their own experiences of looking back on the past. This was seen as an ongoing process of searching for answers as well as questioning their sons’ and at times their own actions. Susan reflected upon her own actions regarding the circumstances surrounding her son’s index offence where he killed his father. Her words in this account demonstrate the enduring nature of her questioning and the ongoing anguish:

Susan: “Still thinking, because, you know, you still think, why, did I not hear? (Susan, pg17) ... Well, you question yourself, uh huh and say, did you do enough, maybe and then you know of course, you say, should he have been admitted, you know and then I felt maybe I should admitted him, you know.” (Susan, pg18)

In a more general sense, Claire and Anne questioned their own actions and responsibility in regards to their son’s difficulties:

Interviewer: “How did it make you feel?”

Claire: “Well I wondered where I went wrong. You know. I think we all blame ourselves if things don’t go, don’t go right.” (Claire, pg 4)

......”So I dunno if the drinkin in his part, done all the damage to [son] or if it was my part with my, as he [ex-husband] says, molly codding.” (Anne, pg29)
Maria described how she has questioned her son’s behaviour especially in relation to his drug use:

Interviewer: “Absolutely, do you think it changed how you saw [son].”

Maria: “Ye I just looked at [son] in a way that you know you think, what happened? Where did it go wrong [son]? Why did you feel you had to go out and take drugs. (Maria, pg 18) ......I know, cos I mean I often lie in bed or anytime and I think, how did that go so badly wrong” (Maria, pg 20)

Evolving relationships

The ever changing nature of the mother son relationship was evident throughout the accounts. This could be seen as a dynamic process and a journey where relationships changed or were lost but have returned. This process has also brought about a sense of acceptance.

“It’s like you were losing him in a sense” - Loss and Change

Each of the mothers described a sense of loss or change that had occurred in their relationships. Much of this appeared to be in relation to the impact of severe mental health difficulties. Susan described her experiences:

“As a parent em, I did worry about him and I knew that there was things going on that wasn’t, you know and I would say because em, he did change then, that was it, it was like you were losing him in a sense and you know and I didn’t have that with the other three.” (Susan, pg 4)
Susan went onto describe how her son’s mental health problems and the associated sense of loss also affected other members of the family. When describing an episode when her son was particularly unwell and she was required to bring him home from where he had been living in England, Susan said:

“I had to go, me and my daughter, [daughter 3], my brother in law phoned and said, [name] he’s, he’s gone, he’s just absolutely gone.” (Susan, pg 8)

Claire reflected on her difficulties in trying to interact and remain close with her son when he was unwell:

_Claire_: “Well it’s been hard. Because it’s hard to get into him. You know it’s hard to get the true [son] because he was unwell, you know {Okay} frustrating”

_Interviewer_: “Frustration?”

_Claire_: “Frustration and a wee sense of loss too.”

_Interviewer_: “What do you think you had lost?”

_Claire_: “[Son]. I just felt I had lost the true [son].” (Claire, pg 8)

From his teenage years, Maria’s son had used drugs and was regularly in trouble with police and she reflected on how this affected their relationship:

“Ye it definitely changes your relationship from a normal kinda everyday ups and downs to this is living with such extreme stress.”(Maria, pg 17)
The evolving nature of relationships is particularly clear within Judith’s account. After the index offence Judith did not see her son for a year. However she has been able to rebuild this relationship and there is a sense that her son is now back:

Judith: “So we didn’t see him for a year and then gradually we went back to seeing him.

Interviewer “So how would you say it impacted on your relationship with [son]?”

Judith: “As I said, now I feel as if I’ve got my son back after all these years.

(Judith pg 17)

“At the end of the day he’s still my son” - Acceptance

All five of the mothers described a sense of acceptance within the relationships with their sons. As described above, after her son’s index offence, when he was first admitted to hospital, Judith felt unable to see her son. She describes how she came to terms with this:

“It took that year, you know I’ll never forget what he did but he’s my son and I love him, you know.” (Judith, pg 17)..... “The hospital kept in touch with me and at the end of the day he’s still my son.” (Judith, pg 18)

When describing her son’s past behaviour and current difficulties, Claire said:

“We are used to that, we are used to that. It’s just the way he’s going to be. And I had to explain to the boys too.” (Claire, pg 9)......”Oh aye, I would never disown him or anything like that. No matter what he does because at the end of the day he’s your son.” (Claire, pg 20)
**Negotiating the conflict between vulnerability and threat**

This theme represents the complex interaction that can exist whereby two contrasting emotions are experienced at the same time- a juxtaposition. This was evident from mothers who experienced their sons as frightening or threatening but also as vulnerable, unwell and in need of care. For some there was a sense of ambivalence within the relationship.

*“You either see it through or you walk away”* - Ambivalence

This sub theme reflects a sense of ambivalence or feeling “caught in the middle” that was experienced by four of the mothers. Maria describes her experiences:

> “Well I just remember thinking this is, this is the big challenges as a mother you either see this through and still support him or sometimes you just feel like I could just walk away.” (Maria, pg 10)

For Anne there was a sense of feeling caught in the middle when her son is detained in hospital against his will. She describes the emotional impact of holding these contrasting emotions at the same time.

> “Well it’s very traumatic and it’s no till you go home that the tears start and you think oh you cannae keep him up there, you cannae do this and cannae do that but he’s got to stay and that’s it.” (Anne, pg 8)

*I feared for his life*

This subtheme represents the sense of being concerned about their sons’ wellbeing and wanting to protect them from harm. All five appeared to have experienced their sons as vulnerable. The profound sense of worry and danger is clear as Claire describes her son’s mental health crisis:
“I feared for his life actually.” (Claire, pg 7)

“Yes, his GP and the Social Worker. And I says I desperately need help, [son] desperately needs help. I says his life could be a risk if he doesnae get the help he needs.” (Claire, pg 10)

Anne described the vulnerability of her son when discussing court proceedings.
There is a sense that he is defenceless, in a literal way with regards his legal status, but also in terms of his mental health difficulties:

“But at the end of it em, the CPN, what’s his name, [cpn]. He em, spoke. He’s the only one that spoke for [son], saying that, you know, that the illness was overtaking him at the time.” (Anne, pg 18)

“You dreaded him coming in”

For three of the mothers, there were times when their sons were perceived as a threat to them. Both Judith and Claire had experiences where they contacted the police regarding their sons:

“You dreaded him coming in. I mean for years when he was young he went through a phase. My husband was frightened to go to sleep.” (Judith, pg 10)

She further described her experiences during her son’s index offence:

“So I phoned the police and I says you’ll need to come up here a says because he’s threatening to shoot us, I says and he’s just attacked dad and I.” (Judith, pg 13)
Claire described the emotional consequences of having to contact the police:

*Interviewer: “How did that feel?”*

*Claire: “It was terrible {okay} Oh ye, guilty for doing it but I was getting to the stage I was going to never speak to him if things didnae improve.”* (Claire, pg 10)

**The emotional realities of being a mother**

The fourth superordinate theme is an important consideration of the various ways that the mothers’ experiences have impacted upon them. It appeared as though the emotional realities were specific to the mothers as there was a sense that their experiences had an added emotional loading, given the longstanding attachment with their sons. It felt as though due to their unique emotional attachments (that comes with the mothering role) there was a heightened emotional turmoil. It is important to consider that experiencing one’s son in distress/trouble will influence the activation of the attachment system and the associated emotions that come with this.

*“My nerves were shattered” - Physical and Emotional Impact*

All five of the mothers explained that their experiences had a physical and/ or emotional impact upon them. Some of the mothers continued to feel this impact. Anne described both her experiences of having to cope with her son’s unusual behaviour and her experiences of court procedures as traumatic:

*“It is still traumatic yet,...... that was at first when they were letting him down from the ward to come down to my house.” (Anne, pg 9).....”Oh the trial. That was traumatic as well.”* (Anne, pg 18).
For three of the mothers, the sense of helplessness coupled with feelings of anger and frustration were apparent when they described their experiences of dealing with services and trying to get help for their sons. Claire describes her experiences:

“Knowing that he needs help and he’s not getting the right help. It was very frustrating. Very very frustrating. And I was angry, I was angry with all the professionals that wereny helping him. (Claire pg 12)

The mothers’ physical health was also affected. Judith developed a number of physical health problems following her difficult experiences with her son. She appears to have come to an understanding about the impact of these events through work with a Psychologist:

..“My nerves were shattered”.....“After that I’d had enough and I just went that’s it. I broke down altogether”..... “She [Psychologist] says your heads that full you cannae cope anymore your head can only cope with so much and it can’t cope any more. So that’s why my body broke down, so that’s why I’ve got a lot of things wrong with me now and over the years.”(Judith, pg 6)

Susan reflected on events shortly following her son’s index offence. When describing police procedures and being interviewed she commented on the impact of this on her:

“And em, I just was physically sick, couldn’t take it all in.” (Susan, pg 15)

She later describes the longer term impact of events:

“I think I was probably interviewed, and spoken to. I probably was lots of times but I don’t quite remember alot about that. I just went through the motions and em, I, did I go back to work? No I didn’t go back to work. I don’t think I went back” (Susan, pg 21)
The confusion and questioning within her own speech also emphasise the difficulties she describes with memory and concentration.

"I was mortified" - Stigma

Stigma and worry about the reaction of others, was an important consideration for four of the mothers. Interestingly there were differing experiences in relation to this. Anne’s use of words clearly indicate how strongly she felt about this:

Anne: “I was mortified. Totally devastated. Mortified. Feart to go out the house. I says, what if anybody knows about us. I mean I dunno how much people know to this day cos I never ever discussed it with anybody. I telt my bingo cronies and that, that he was away and I says that he wasnae keepin that well and that and he was in the hospital, I says, but it’ll be a matter of time. They did know there was a trial about it.” (Anne, pg13)

However she also highlighted concerns about other’s opinions of mental illness more generally:

Anne: “Aye, others, cos they don’t understand. I mean this awareness of mental health and that, how many people is aware of it. I mean I wouldnae be aware if he didnae” (laughs). (Anne, pg 26)

In contrast, when Susan was asked about her experiences of being involved with forensic services, she was clear that she did not feel there is a stigma:

“But I must admit, I haven’t, right, we are in that and that is the word. I don’t feel it, I don’t feel that there is you know a, what’s the word I’m looking for. A stigma that I’m, we are a you know, under the forensic services. I really don’t feel that that was you know. I mean initially when we were questioned and the
police were around but that only lasted the week, that felt, that was horrible, that was just, d’you know.” (Susan, pg28)

Discussion

This study examined the experiences of caregiving from the perspective of mothers of service users supported within a forensic mental health service. Specifically, it investigated how they made sense of their experiences, roles and relationships. Each of the mothers had gone through a process of trying to come to terms with past events. This appeared to have been helpful by providing understanding, clarity, certainty and a sense of acceptance. Some uncertainty has remained and the mothers continued to search for answers and explanations for what has happened. The mothers described evolving relationships with their sons and a sense that they had been through a journey of change, loss and acceptance. For most there was a sense that for a time their sons were lost but that they have now returned. One of the challenges for the mothers had been in negotiating the conflicting and complex emotions and sense of ambivalence that has emerged due their sons’ mental illness, offending behaviour and lifestyle choices. The mothers have been able to negotiate these challenges, through having a strong sense of identity as a mother. These experiences have not been without consequences and the mothers described the physical and emotional impact of these as well the resulting sense of stigma.

The process of coming to terms with what happened

The idea that the mothers went through a process to try to come to terms with events resonates with findings by Nordstrom et al. (2006). They used grounded theory to examine parents’ experiences of caring for adult children with a diagnosis of schizophrenia and a history of violent crime. They found that parents went through different stages with their
adult children and that these stages elicited different emotions and behaviour. In particular they found that in response to the onset of mental illness and the diagnosis of schizophrenia, they attempted to search for causes or search for information. This has similarities with the mothers in the current study in terms of them searching for causes, however in the current study, this was at a more personal level and often related to making sense of the index offence. Mothers were considering their own actions and that of their sons in trying to understand more clearly rather than searching for information. It appears that the mothers in the current study have engaged in the process of trying to make sense of their experiences and this has helped provide explanations and a degree of certainty and acceptance. Indeed Charlesworth and Reichelt (2004) have stated “caregivers are often looking for ways to make sense of both their own and the care recipient’s emotional and behavioural reactions” (pg 403). They go on to suggest that the use of formulation can help relatives to understand the experiences of people with mental health problems.

**Evolving Relationships**

The mothers described changing relationships as well as a sense of loss and acceptance within the relationships with their sons. This sense of loss resonates with findings by Paterson, et al. (2005), who found that carers of those experiencing a first episode of psychosis experienced a great sense of loss, comparable to levels recorded in physical bereavement. Similarly, Ryan (1993) and McCann, Lubman and Clark (2011) found this to be a key theme in their qualitative studies of caregivers’ experiences of caring for relatives with schizophrenia. These findings were also evident within a forensic context (Nordstrom et al., 2006).
Negotiating the conflict between vulnerability and threat

The factors highlighted within this superordinate theme emphasised that there can be added complexities within caregiving relationships in the forensic context. Subthemes related to mothers feelings of ambivalence towards their sons, as well as experiences of sons as threatening but also vulnerable. These findings relate to findings by Nordstrom et al. (2006), one of their themes related to violence and criminality. They found that some parents were victims of their relatives offending and also described feelings of anger and fear, however interestingly; the parents rarely reported these incidents. For them there was a sense that “you don’t report your own son to the police”. The idea of having two different emotions at the same time was also highlighted by Nordstrom et al. (2006). After her son was convicted of murder, one parent reported that she separated her son into two people in her own mind, she felt angry towards him but also acknowledged that he was mentally unwell. James (1996) found that often family members are the victims of their relatives’ violence. He suggested that the ambivalence that this may bring about can add to the sense of burden for the family member.

A small number of studies have examined caregiving in a forensic context (Nordstrom et al., 2006: Ridley et al., 2014), and the current study has been able to build upon this to help more readily understand the experiences of carers in forensic settings. However in investigating mothers’ experiences in particular, there has been a focus on the more interpersonal and relational aspects of caregiving. Further understanding of the important role of a mother in this context gives insight into how the attachment and caregiving systems may operate. Of particular interest has been the consideration of having to negotiate the conflict between vulnerability and threat. This is important given that family members are often the victims of their relatives’ offending behaviour. This presents a quandary for mothers as has been seen in the current study. The sense of wanting to go to a
son to protect him while also feeling frightened and wanting to flee has interesting implications, certainly when considering the caregiving system. It is important to consider the many difficult emotional responses that this situation can engender. Experiencing feelings of fear about your own safety while at the same time worrying about the wellbeing of your son coupled with feelings of guilt, responsibility and shame present as an overwhelming situation that is often faced by mothers. This study has been able to provide some insight into this and how mothers have coped, made sense of and come to terms with these experiences. However further examination of this and the consequences of being “caught in the middle” is required to build upon this.

The emotional realities of being a mother
It was clear from all of the mothers’ accounts, that their experiences had had a significant impact upon them. They reflected upon the emotional and physical consequences of past events as well as experiences with the legal system and psychiatric services. Indeed, Tsang et al. (2002) has suggested that carers of those within the forensic system may suffer additional stress and that this may come from having to cope with police, court and legal proceedings. These findings are also in line with results from studies of caregiving in psychosis, which found that relatives often find their experiences traumatic (Barton & Jackson, 2008) with increased feelings of burden, distress and worry (Scazufca & Kuipers, 1996; Gupta, Solanki, Koolwal & Gehlot, 2015; Reed, 2008; Addington, Coldham, Jones, Ko & Addington, 2003; Brown & Birtwistle, 1998; Riock et al., 2007.)

When considering the impact of tireless efforts to get help from services, mothers described feelings of helplessness, desperation, fear and anger. Mother’s felt that services were not doing enough to help their sons and that often they recognised that their sons were not well but this was not acknowledged or acted upon by services. For some the concern was for their physical health with one mother continuing to suffer from serious medical problems which she linked causally to the experience of caring for her son. This is
in line with findings which suggest that caregiving can have detrimental effects on the body (Vitaliano, Zhange & Scanlan, 2003; Schulz & Sherwood, 2008).

James (1996) has suggested that at least two factors, namely violence and stigma, may further add to problems faced by relatives of those seen with the forensic mental health system. Two of the mothers reflected upon the idea of stigma. For one mother there was a clear sense of shame around her son’s conviction, describing that she was “mortified”, while one mother explained that she did not feel a sense of stigma. Past studies have shown stigma to be a key source of distress in caregivers of those suffering from psychosis (Ryan, 1993; McCann et al., 2011; Kuipers et al., 2010). For carers with relatives within the forensic system there may be an added dimension of stigma relating to convictions or offending behaviour. The idea that others may perceive their relative as “mad” and “bad” (Tsang et al., 2002; Trute, Tefft & Segall, 1989) may add substantial amounts of stress and shame. Work by Ridley et al., (2014) also highlights the impact of the caring role on carers. They investigated the views of 66 forensic carers from throughout Scotland. They found that carers carried significant emotional burden and that they often felt stigmatised with some experiencing isolation within their own communities. The finding within the current study that one mother did not feel this sense of stigma seems contrary to what others have reported. This is an area that warrants further investigation.

**Clinical Implications**

There is substantial evidence that family approaches can influence outcome and relapse in mental health problems (Falloon, 2003). Having a better understanding of experiences of caregiving is useful in terms of highlighting potential areas for intervention for both service users and carers. The mothers appeared to have gone through a process of making sense of their experiences, much akin to the process of psychological formulation. Having
carers more involved with the formulation and intervention process may be of particular benefit not only to them but also to the service user and services. It would give the opportunity for their caregiving experiences to be integrated and considered in more detail. In a forensic service this could also have important implications for risk management as carers may be more likely to be the victim of violence in the future and less likely to report it. Having carers more engaged with the formulation, intervention and management may help to reduce future risk of harm.

It will be important for services to more readily understand mothers’ experiences of caregiving and how this has shaped their understanding and coping. Examination of these experiences could help services shape their responses to carers and improve experiences for carers. The importance of supporting and including carers has been emphasised within health and social care policy however it is important that policy makers and service providers take full consideration of the experiences of carers and the impact of caring. The findings of the present study appear to support existing literature which emphasis the increased burden on carers in a forensic setting. This will be important if the needs of these individuals are to be truly met.

Limitations

Findings were based on a small homogenous sample of individuals who agreed to be interviewed. This limits the generalisability of the findings but is however in accordance with the principles of IPA. Although IPA does not aim to be generalisable, the mothers who chose to participate all perceived their current relationship with their son’s to be positive and it may be that those with less positive relationships chose not to take part. It would have been interesting to explore the experiences of those who did not have such a positive relationship with their relative in order to provide an added insight and possibly a different perspective. Similarly, none of the mothers’ relatives were female and it would have been interesting to explore the relationships between mothers and daughters. A
further limitation which is evident in all qualitative research is the influence of subjectivity, interpretation and bias. In order to address this, the researcher completed a reflective log throughout the process and received regular supervision. In addition to this, a check of validity was conducted by the research supervisor. Although these measures can be put in place it must be highlighted that the researcher would never be able to do a completely objective analysis of the data.

**Future Research**

Given the complexities that are often present within forensic contexts it is particularly important to have an in depth understanding of the experiences and perspectives of carers. It will be useful to understand how these experiences may resonate or differ with other groups. Much of the research has focussed on more general mental health services, with less focus on more specialised areas. Due to the paucity of qualitative research investigating carers experiences of caregiving with a forensic context, it is recommended that further research is conducted to replicate, develop or add to the themes found in this study. This study investigated mothers experiences of caregiving however it would also be interesting to investigate the experiences of carers, who are not mothers.

Future research should be carried out within forensic settings in order to unpick and further understand carers’ experiences. Qualitative methodology will facilitate this process. In future studies, this could be built upon such that it may be possible to develop a caregiving questionnaire specific to forensic settings. Having a well validated questionnaire measure could be used in future research and in clinical practice. When considering future research, an added benefit of having a more thorough understanding of caregiving is that it could help to develop our understanding of other clinical models, for example, the attribution model of relapse (Barrowclough, Johnston & Tarrier, 1994).
Conclusions

This study explored what it’s like for mothers to have sons within Forensic Mental Health Services. Specifically it examined how they made sense of their relationships, roles and experiences. Participants’ accounts demonstrated that they had gone through a process of coming to terms with past events and offending behaviour. It was evident however that the mothers continued to engage in a process of searching for answers and questioning what had happened. The mother’s reflections highlighted the complex nature of their caregiving relationships but also how these had impacted upon them. A number of the themes were found to be consistent with those of other studies examining caregiving within forensic settings but also within more generalised psychiatric settings. A number of the themes identified highlighted areas that have received less focus in previous studies and these warrant further investigation. The current study highlights implications for clinicians, healthcare providers and policy makers. Areas for future research are also identified.
References


Appendices

**Appendix 1** - Summary of Author Guidelines for Submission to The Journal of Forensic Psychiatry & Psychology

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**The Journal of Forensic Psychiatry & Psychology**

**Aims and scope**

The *Journal of Forensic Psychiatry and Psychology* is a multidisciplinary journal devoted to publishing papers relating to aspects of psychiatry and psychological knowledge (research, theory and practice) as applied to offenders and to legal issues arising within civil, criminal, correctional or legislative contexts.

Throughout the world, psychiatrists, psychologists, criminologists, lawyers, sociologists, nurses, social workers and other legal and medical professionals use this journal as their major forum for penetrating, informed global debate on the latest developments and disputes affecting the practice of forensic psychiatry.

The *Journal of Forensic Psychiatry and Psychology* publishes in-depth case studies, current research and short articles on mental health, crime and the law. This acclaimed journal is essential to all serious psychiatric or legal collections.

**Peer Review:** All submitted manuscripts are subject to initial appraisal by the Editor, and, if found suitable for further consideration, to peer review by independent, anonymous expert referees. All peer review is double blind and submission is online via ScholarOne Manuscripts.

**Instructions for authors**

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

**About the journal**

*The Journal of Forensic Psychiatry & Psychology* is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal’s Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

This journal accepts the following article types: original manuscripts; case reports; brief reports; review articles; book reviews; and review essays.

**Peer review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer-reviewed by independent, anonymous expert
referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

Structure

Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Word limits

Please include a word count for your paper.

A typical manuscript for this journal should be no more than 5000 words; this limit does not include references.

Review papers (e.g. systematic reviews, meta-analyses, law reviews) and some empirical studies may require greater length and the Editors are happy to receive longer papers.

We encourage brevity in reporting research.

A typical brief report for this journal should be no more than 2000 words; this limit includes references. Normally, there should be a maximum of one table.

Style guidelines

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling style consistently throughout your manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Section headings should be concise.

Formatting and templates

Papers may be submitted in any standard format, including Word. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting templates.
**Word templates** are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact authortemplate@tandf.co.uk

**References**

Please use this reference style guide when preparing your paper. An *EndNote output style* is also available to assist you.

**Checklist: what to include**

1. **Author details.** Please include all authors’ full names, affiliations, postal addresses, telephone numbers and email addresses on the title page. Where available, please also include [ORCID identifiers](https://orcid.org) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors’ affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship.](#)

2. A non-structured **abstract** of no more than 200 words. Read tips on [writing your abstract](#).

3. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming.](#)

4. **3 –6 keywords.** Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.

5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   - **For single agency grants:** This work was supported by the [Funding Agency] under Grant [number xxxx].
   - **For multiple agency grants:** This work was supported by the [Funding Agency 1]; under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding Agency 3] under Grant [number xxxx].

6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. [Further guidance on what is a conflict of interest and how to disclose it](#).

7. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper’s study area accurately in [JournalMap’s geographic literature database](https://journalmap.org) and [make your article more discoverable to others](#).
8. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article](#).

9. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be saved as TIFF, PostScript or EPS files. More information on [how to prepare artwork](#).

10. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

11. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).

12. **Units.** Please use SI units (non-italicized).

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### Submitting your paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in the submission centre. Please read the guidelines above and then [submit your paper in the relevant author centre](#) where you will find user guides and a helpdesk.

Please note that *The Journal of Forensic Psychiatry & Psychology* uses CrossRef™ to screen papers for unoriginal material. By submitting your paper to *The Journal of Forensic Psychiatry & Psychology* you are agreeing to originality checks during the peer-review and production processes.

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**Queries**

Should you have any queries, please visit our Author Services website or contact us at authorqueries@tandf.co.uk.
## Appendix 2- Risk of Bias Tool

<table>
<thead>
<tr>
<th>Domain</th>
<th>Tool Item Must address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods for selecting study participants</td>
<td>Appropriate source population and inclusion or exclusion criteria</td>
</tr>
<tr>
<td>Methods for measuring exposure and outcome variables</td>
<td>Appropriate measurement methods for both exposure(s) and/or outcome(s)</td>
</tr>
<tr>
<td>Methods to control confounding</td>
<td>Appropriate design and/or analytical methods</td>
</tr>
<tr>
<td>Statistical methods (excluding control of confounding)- sample size determination</td>
<td>Appropriate methods outlined to deal with sample size determination</td>
</tr>
<tr>
<td>Statistical methods (excluding control of confounding)- assumptions of statistical tests</td>
<td>Appropriate methods outlined to deal with assumptions of statistical tests</td>
</tr>
<tr>
<td>Statistical methods bias (excluding confounding)- multiple testing</td>
<td>Appropriate methods outlined to deal with multiple testing</td>
</tr>
<tr>
<td>Statistical methods (excluding control of confounding)- clustering</td>
<td>Appropriate use of statistics to deal with clustering/relatedness of data</td>
</tr>
<tr>
<td>Overall Risk of Bias</td>
<td>If two or more categories rated as high then overall risk is High</td>
</tr>
</tbody>
</table>
## Appendix 3- Detailed breakdown of Risk of Bias Ratings

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods for selecting study participants</th>
<th>Methods for measuring exposure and outcome variables</th>
<th>Methods to control confounding</th>
<th>Statistical methods (excluding control of confounding) - Sample size determination</th>
<th>Statistical methods (excluding control of confounding) - Assumptions of tests</th>
<th>Statistical methods (excluding control of confounding) - Multiple testing</th>
<th>Statistical methods (excluding control of confounding) - Clustering</th>
<th>Overall Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beazley and Gudjonsson (2011)</td>
<td>Good description of sample and its characteristics. Good description of inclusion/exclusion and numbers declined. All patients were considered except those judged by team to be too mentally unwell. Recruited from a medium secure unit-6 wards LOW</td>
<td>Reported reliability scores for measures Well validated/reliable measures.</td>
<td>Acknowledge interrelationship between variable. Used depression as a control for motivation</td>
<td>Mentions regression model is less sensitive to outliers and variations of normality than other regression models and therefore have increased power. But no specific calculation given. UNCLEAR</td>
<td>Mentions regression model is less sensitive to outliers and variations of normality than other regression models</td>
<td>No mention</td>
<td>Used correlations and regression. Lack of control for clustering of data</td>
<td>HIGH</td>
</tr>
<tr>
<td>Bressington et al (2011)</td>
<td>Clear mention of inc/exc criteria. Asked all service users utilising forensic in patient Measures well described. Well validated/reliable measures</td>
<td>Didn’t specify and control for confounding factors that might affect satisfaction such as</td>
<td>No mention of power/sample size determination</td>
<td>No mention</td>
<td>No mention</td>
<td>Correlations No regression</td>
<td>Lack of</td>
<td>HIGH</td>
</tr>
<tr>
<td>Study</td>
<td>Clear description of sample and reasons/numbers excluded for various reasons and numbers who declined to take part. Clear/appropriate inc/exc. Those without capacity was</td>
<td>Well validated/reliable measures</td>
<td>Excluded those who had been in ward for less than 3 months</td>
<td>Controlled for negative affect.</td>
<td>No mention of power/sample size determination</td>
<td>No mention</td>
<td>Adjustment was made-Bonferroni</td>
<td>Did correlations then regression</td>
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<tr>
<td>Campbell et al (2014)</td>
<td>care in the directorate to participate, only exclusion was if clinical team viewed person as not being able to complete assessments. Good general description of sample characteristics/ and numbers declined. Doesn’t give number that were not eligible Low response rate/small sample size HIGH</td>
<td>LOW</td>
<td>HIGH</td>
<td>HIGH</td>
<td>HIGH</td>
<td>LOW</td>
<td>HIGH</td>
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</table>

- "High" indicates a strong feature.
- "Low" indicates a weak feature.
- "No mention" indicates that the feature is not discussed in the study.
<table>
<thead>
<tr>
<th>Study</th>
<th>Exclusion criteria (as judged by clinicians)</th>
<th>Sample covered</th>
<th>Well validated/ reliable measures.</th>
<th>To assess the relationship between patient characteristics and ward atmosphere path analyses were conducted using Mplus v7.0</th>
<th>No mention of power/sample size determination</th>
<th>No mention</th>
<th>No mention</th>
<th>Used regression</th>
<th>Lack of control for clustering of data</th>
</tr>
</thead>
<tbody>
<tr>
<td>de Vries et al (2016)</td>
<td>Those without capacity excluded- most unwell may have had a different influence</td>
<td>4 medium secure units across 3 NHS trusts</td>
<td>Reports reliability scores for the EssenCES</td>
<td>Reported confidence intervals</td>
<td>HIGH</td>
<td>N/A</td>
<td>HIGH</td>
<td>Used regression</td>
<td>HIGH</td>
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<td></td>
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<td></td>
<td></td>
<td>Lack of control for clustering of data</td>
<td></td>
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<tr>
<td>Study</td>
<td>Good description of inc/exc criteria and sample characteristics.</td>
<td>Well validated/ reliable measures</td>
<td>Controlled for gender and level of security to improve generalisability.</td>
<td>Reports power/ sample size determination</td>
<td>Reports that assumptions of tests were met, eg. Normality/ multicollinearity</td>
<td>Deals with multiple testing by saying they used regression</td>
<td>Used regression</td>
<td>Lack of control for clustering of data</td>
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<tr>
<td>Dickens et al (2014)</td>
<td>Doesn’t give breakdown of reasons/proportions for non participation. Selection bias= those more unwell/aggressive may not be included One hospital, 13 wards, different security levels. Suitable sample size</td>
<td>LOW</td>
<td>No SEM</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>HIGH</td>
<td></td>
</tr>
<tr>
<td>Livingston et al (2012)</td>
<td>Good description of sample characteristics and inc/exc criteria. Those most risky/unwell may not be represented. Small sample size Doesn’t give detail of numbers/ reasons</td>
<td>LOW</td>
<td>Low response rates</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>LOW</td>
<td>HIGH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>for non participation</td>
<td>confounding factors e.g. mood / diagnosis/symptom severity, security level, gender</td>
<td>Measures valid/reliable.</td>
<td>Didn’t specify and control for confounding factors e.g. mood/ symptom severity/ level of security, diagnosis/ time on the ward</td>
<td>No mention of power/ sample size determination</td>
<td>No specific mention but does use spearman’s rho for correlation – indicating use of non-parametric methods.</td>
<td>No mention</td>
<td>Used correlations and then regression</td>
<td>Lack of control for clustering of data</td>
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<tr>
<td>Long et al (2011)</td>
<td>Not much detail of inc/exc but just that all staff and patients were eligible.</td>
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<tr>
<td></td>
<td>Good description of sample</td>
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<tr>
<td></td>
<td>Didn’t give details of who didn’t participate.</td>
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<td></td>
<td>Same hospital - 2 low (49 beds) and 2 medium secure (28 beds) wards</td>
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<td></td>
<td>LOW</td>
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<td></td>
</tr>
<tr>
<td>Ros et al</td>
<td>Not a lot of detail on the actual sample characteristics or inclusion/exclusion criteria.</td>
<td>Well validated/reliable measures</td>
<td>To investigate relations between ward-atmosphere and incidents, a SEM was fitted to the data, using a cross-lagged panel design</td>
<td>No mention of power/sample size determination</td>
<td>No mention</td>
<td>No mention</td>
<td>Described method for handling missing data</td>
<td>Lack of control for clustering of data</td>
<td>HIGH</td>
</tr>
</tbody>
</table>
Appendix 4- Ethics Approval letter and Amendments

Mrs Fiona Scott
Trainee Clinical Psychologist
NHS Lanarkshire
Caird House
Caird Street
Hamilton
ML3 0AL

West of Scotland REC 3
West of Scotland Research Ethics Service
West Glasgow Ambulatory Care Hospital
(former Royal Hospital for Sick Children Yorkhill)
Dalmair Street
Glasgow G3 8SW
www.nhsrggc.org.uk

Date  23rd November 2016
Your Ref
Our Ref
Direct line  0141 232 1805
E-mail  WOSREC3@ggc.scot.nhs.uk

Dear Mrs Scott

| Study title: | What’s it like having a son or daughter in Forensic Mental Health Services? An Interpretative Phenomenological Analysis of mothers’ experiences |
| REC reference: | 16/WS/0204 |
| Protocol number: | L16058 |
| IRAS project ID: | 207941 |

Thank you responding to the letter regarding additional conditions of approval. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 02 November 2016

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview schedules or topic guides for participants [Interview Schedule]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Other [Staff Information Sheet]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Other [Contact Slip]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Participant consant form [consent form]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [PIS]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Research protocol or project proposal [MRP Proposal/Protocol]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
</tbody>
</table>

Approved documents

The final list of approved documentation for the study is therefore as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copies of advertisement materials for research participants</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
<tr>
<td>Item Description</td>
<td>Quantity</td>
<td>Date</td>
</tr>
<tr>
<td>------------------</td>
<td>----------</td>
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</tr>
<tr>
<td>Copies of advertisement materials for research participants</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Interview Schedule]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Letter from sponsor [Sponsorship Confirmation Letter]</td>
<td>1</td>
<td>31 August 2016</td>
</tr>
<tr>
<td>Other [Ken MacMahon CV]</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
<tr>
<td>Other [Demographic questions]</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
<tr>
<td>Other [Stuff Information Sheet]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Other [Contact Slip]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Participant consent form [consent form]</td>
<td>2</td>
<td>11 November 2016</td>
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<tr>
<td>Participant information sheet (PIS) [PIS]</td>
<td>2</td>
<td>11 November 2016</td>
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<tr>
<td>REC Application Form [REC_Form_22092016]</td>
<td></td>
<td>22 September 2016</td>
</tr>
<tr>
<td>Referee’s report or other scientific critique report [University Blind Review Feedback]</td>
<td>1</td>
<td>31 August 2016</td>
</tr>
<tr>
<td>Referee’s report or other scientific critique report [University Proceed to Ethics Letter]</td>
<td>1</td>
<td>31 August 2016</td>
</tr>
<tr>
<td>Research protocol or project proposal [MRP Proposal/Protocol]</td>
<td>2</td>
<td>11 November 2016</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (C) [Fiona Scott CV]</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [Andrew Gumley CV]</td>
<td>1</td>
<td>29 July 2016</td>
</tr>
</tbody>
</table>

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor’s responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

16/WS/0204 Please quote this number on all correspondence

Yours sincerely,

Liz Jamieson
REC Manager

Copy to: Mr Raymond Hamill, NHS Lanarkshire
Dear Mrs Scott

Study title: What’s it like having a son or daughter in Forensic Mental Health Services? An Interpretative Phenomenological Analysis of mothers’ experiences

REC reference: 15/WS/0204
Amendment number: AM01
Amendment date: 27 January 2017
IRAS project ID: 207941

Thank you for your letter of 27 January 2017, notifying the Committee of the above amendment – Version 2 of the Consent Form corrected in respect of the Version and date of the Participant Information Sheet.

The Committee does not consider this to be a “substantial amendment” as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notice of Minor Amendment [Email ]</td>
<td>AM01</td>
<td>27 January 2017</td>
</tr>
<tr>
<td>Participant consent form</td>
<td>3</td>
<td>27 January 2017</td>
</tr>
</tbody>
</table>

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.

16/WS/0204: Please quote this number on all correspondence
Yours sincerely

Liz Jamieson
REC Manager

Copy to: Mr Raymond Hamill, NHS Lanarkshire
Appendix 5 - NHS R&D Approval letter and Amendments

NHS Lanarkshire Research & Development: Management Approval Letter

Mrs Fiona Scott
Trainee Clinical Psychologist
NHS Lanarkshire
Caird House
Caird Street
Hamilton
ML3 0AL

R&D Department
Corporate Services Building
Monklands Hospital
Monkscouri Avenue
AIRDRIE
ML6 0JS

Date: 25.11.16
Enquiries to: Elizabeth McGonigal,
R&D Facilitator
Direct Line: 01236 712445
Email: elizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Fiona

Project title: What's it like having a son or daughter in Forensic Mental Health Services? An Interpretative Phenomenological Analysis of mothers' experiences

R&D ID: L16058

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

<table>
<thead>
<tr>
<th>NAME</th>
<th>TITLE</th>
<th>ROLE</th>
<th>NHSL SITE TO WHICH APPROVAL APPLIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Fiona Mair</td>
<td>Clinical Psychologist</td>
<td>Local Collaborator</td>
<td>NHS Lanarkshire</td>
</tr>
</tbody>
</table>

As you are aware, NHS Lanarkshire has agreed to be the Sponsor for your study. On its behalf, the R&D Department has a number of responsibilities; these include ensuring that you understand your own role as Chief Investigator of this study. To help with this we have outlined the responsibilities of the Chief Investigator in the attached document for you information.

All research projects within NHS Lanarkshire will be subject to annual audit via a questionnaire that we will ask you to complete. In addition, we are required to carry out formal monitoring of a proportion of projects, in particular those projects that are Sponsored by NHS Lanarkshire. In either case, you will find it helpful to maintain a well organised Site File. You may find it helpful to use the folder that we have included for that purpose.

L16058_ManagementApproval_251116  Page 1 of 3  Cont...
For the study to be carried out you are subject to the following conditions:

**Conditions**

- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.show.scot.nhs.uk/cso/ or the Research & Development Intranet site: http://firstport/sites/randd/default.aspx.
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

<table>
<thead>
<tr>
<th>NAME</th>
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<tbody>
<tr>
<td>Dr Fiona Mair</td>
<td>Clinical Psychologist</td>
<td><a href="mailto:Fiona.Mair@lanarkshire.scot.nhs.uk">Fiona.Mair@lanarkshire.scot.nhs.uk</a></td>
<td>Local Collaborator</td>
</tr>
<tr>
<td>Raymond Hamill</td>
<td>Corporate R&amp;D Manager</td>
<td><a href="mailto:Raymond.Hamill@lanarkshire.scot.nhs.uk">Raymond.Hamill@lanarkshire.scot.nhs.uk</a></td>
<td>Sponsor Contact</td>
</tr>
</tbody>
</table>
**Responsibilities as Sponsor**

**Site File**
As an aid to the conduct of your study we have provided a Site File that you may wish to use. As Sponsor of the study we are required to carry out audit of all project, and to conduct detailed monitoring visits for a proportion (approximately 10%) - The study Site File should help you ensure that you have the relevant documentation to assist in this process. If your project is selected for monitoring, we will contact you well in advance to arrange a suitable time.

Our responsibilities as Sponsor are defined within the Research Governance Framework for Health and Community Care. A summary of these, along with those of the Chief Investigator, is provided in the following table for your information.

<table>
<thead>
<tr>
<th>RESPONSIBILITIES OF CHIEF INVESTIGATOR</th>
<th>NHSL RESPONSIBILITIES AS SPONSOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain relevant / appropriate Research Ethics opinion.</td>
<td>Assess adequateness of the independent, expert review.</td>
</tr>
<tr>
<td>Obtain NHSL Research Management Approval.</td>
<td>Ensure that the Chief/Principle Investigator has the necessary expertise, experience and education to conduct the study.</td>
</tr>
<tr>
<td>Ensure that the members of the research team have the necessary expertise, experience and education to perform their roles.</td>
<td>Provide a formal written agreement of sponsorship conditions, and notification of confirmation of the sponsorship role.</td>
</tr>
<tr>
<td>Ensure the necessary resources are available for the study.</td>
<td>Provide NHS indemnity to the Chief Investigator and research team.</td>
</tr>
<tr>
<td>Act in accordance with regulations set out by your professional body(s) and the conditions of your employment contract.</td>
<td>Provide mechanisms and processes to exploit any potential Intellectual Property.</td>
</tr>
<tr>
<td>Identify archiving arrangements at the study outset.</td>
<td>Project monitoring commensurate with risk.</td>
</tr>
<tr>
<td>Record and review significant developments that may affect the study, particularly those which put the safety of the individuals at risk or affect the scientific direction and report to the sponsor as appropriate.</td>
<td>Make available local, national and international guidelines, regulations and legislation governing research in the UK.</td>
</tr>
<tr>
<td>Record, report and review all untoward medical occurrence (adverse events or reactions) including classification of causality, seriousness and expectedness.</td>
<td>Provide ongoing advice and guidance to promote quality study management and conduct.</td>
</tr>
<tr>
<td>Notify R&amp;D and appropriate REC of significant news, changes, amendments and modifications to the study.</td>
<td>Determine the acceptability of the archive arrangements proposed by the Chief Investigator and, if the archive facility becomes unsuitable, provide alternative arrangements.</td>
</tr>
<tr>
<td>Maintain a record of all incidents, providing an annual report to the sponsor.</td>
<td>Determine length of archive/retention period for essential study documents and subsequent destruction date.</td>
</tr>
<tr>
<td>Inform REC and R&amp;D of the study end.</td>
<td></td>
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<tr>
<td>Maintain a log of archived documents and their location.</td>
<td></td>
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<tr>
<td>Inform R&amp;D of any publications arising from the study or dissemination of findings.</td>
<td></td>
</tr>
<tr>
<td>Inform R&amp;D of any potential Intellectual Property.</td>
<td></td>
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</tbody>
</table>
Mrs Fiona Scott  
Trainee Clinical Psychologist  
NHS Lanarkshire  
Caird House  
Caird Street  
Hamilton  
ML3 0AL

R&D Department  
Corporate Services Building  
Monklands Hospital  
Monkscouth Avenue  
AIRDRIE  
ML6 0JS

Date  
9 February 2017

Enquiries to  
Elizabeth McGonigal, R&D Facilitator

Direct Line  
01236 712459

Email  
eilizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Mrs Scott:

Project title: What’s it like having a son or daughter in Forensic Mental Health Services? An Interpretative Phenomenological Analysis of mothers’ experiences

R&D ID: L16058  
Ethics number: 16/WS/0204

Amendment number: AM01, 27.01.17  
Ethics acknowledgement date: 27.01.17

Local PI: Dr Fiona Mair  
NHSL Site(s): NHS Lanarkshire

I am writing to you as Chief Investigator of the above study in reference to the above Amendment as approved in the Ethics Acknowledgement letter dated 27.01.17. Any documents approved are listed in Table 1, overleaf.

I confirm that your original R&D Management Approval has not been affected by this Amendment, and it can therefore be implemented within NHS Lanarkshire as detailed above, subject to all regulatory approvals. NHS Lanarkshire reserves the right to revoke Management Approval should any unfavourable opinions be received.

I note that it is the responsibility of the Principal Investigator(s) to carry out any changes to be made to the project as a result.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

cc. – see overleaf

PLEASE NOTE: It is the responsibility of the Principal Investigator to inform the R&D Department of any significant findings identified as a result of a Monitoring Visit.
Table 1. Documents approved by the NHS REC as part of this amendment

<table>
<thead>
<tr>
<th>Document</th>
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</tr>
<tr>
<td>Raymond Hansel</td>
<td>Corporate R&amp;D Manager</td>
<td><a href="mailto:Raymond.Hansel@lanarkshire.scot.nhs.uk">Raymond.Hansel@lanarkshire.scot.nhs.uk</a></td>
<td>Sponsor Contact</td>
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</table>
Appendix 6- Participant Information Sheet

PARTICIPANT INFORMATION SHEET (Version 2.0, 11/11/2016)

What’s it like having a son or daughter in Forensic Mental Health Services?

Thank you for reading this information sheet. I would like to invite you to take part in a research study. My name is Fiona Scott and I am undertaking research investigating mothers’ experiences of caregiving in a forensic context. I am a student at the University of Glasgow and this research project is in part fulfillment of my Doctorate in Clinical Psychology. I would very much appreciate if you would take the time to read this information sheet and consider taking part in this study.

What is the purpose of the study?

The study is a collaboration between the University of Glasgow, NHS Lanarkshire and Support in Mind Scotland. The aim of the study is to gain a better understanding of mothers’ experiences of caregiving for sons or daughters who are seen within Forensic Mental Health Services.

Why have I been asked to take part?

You have been asked to participate because you are the mother of an individual supported within Forensic Mental Health Services.

Do I have to take part?

No you do not need to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your legal rights or the care of your son or daughter.

What will happen to me if I take part?

If you do decide to take part, you will be invited to an interview near where you live. You will be asked to sign a consent form. The interviews are expected to last for about 60 minutes. The interviews will be recorded. If you wish, I will contact you one week after the interview to discuss any issues or concerns that may have arisen during the interview. If required, we can also discuss possible sources of support that may be available to you.

Will my taking part in this study be kept confidential?
All of the information gathered will be kept confidential with only my supervisors and I having access to it. I will ask for some personal details such as your name and age as well as some other demographic details.

Each participant will then be given a code as a means of identifying them, rather than their name. This is necessary in case any participant decides to withdraw from the study and I need to remove their data. The link between participants’ names and code numbers will be kept in a locked filing cabinet within the Institute of Mental Health and Wellbeing, Gartnavel Royal Hospital. The recordings from the interview will be transcribed, made anonymous, and then destroyed.

The anonymous transcripts will be stored on an encrypted password protected computer. No identifiable information will be included in the publication of this research.

If you share information that makes me concerned for your safety or the safety of other people, I may be required to tell others (e.g. your General Practitioner). I will always endeavour to discuss this with you beforehand if I am going to do this, and explain why.

What will happen to the results of the research study?

It is anticipated that the results of the study will be published and/or presented in a variety of forums. It will also form part of my qualification of Doctorate in Clinical Psychology. In any publication and/or presentation, information will be provided in such a way that neither you nor your relative can be identified.

Who is organising and funding the research?

NHS Lanarkshire is acting as Sponsor for the research. It is being completed as part of my Doctorate in Clinical Psychology.

Who has reviewed the study?

The study has been reviewed by the University of Glasgow and the West of Scotland Research Ethics Committee to ensure that it meets standards of ethical conduct. Approval has been granted by NHS Lanarkshire Research and Development department.

Are there any benefits to taking part?

There are no direct benefits to you for taking part in this study. However, the information that you provide will help our understanding of how mothers experience caregiving for their sons or daughters in a forensic context. It will help us to work out how best to support individuals within this context and develop better psychological care and support for patients and their families.

Are there any down sides to taking part?

It is possible that our discussion may trigger upsetting thoughts of feelings that may be difficult for you to talk about. If this is the case, and you wish to stop, you can end the interview at any time. If you need a break during the interview this is okay. If you become upset or distressed as a result of
your participation in the research, I will be able to support you and signpost you to appropriate support networks and services.

**What if I withdraw from this research study?**

You can withdraw from the study at any time. You do not have to provide a reason and if you withdraw this will have no effect on the care of your family member.

If you do withdraw from the study, any personally identifiable information about you will be destroyed. However, anonymised data already collected will be retained to ensure that the results of the research project can be measured properly. You should be aware that data collected up to the time that you withdraw will form part of the research project results. If you do not want them to do this, you should choose not to participate in this study.

**What will happen if there is a problem or if I want to make a complaint?**

If you have any concerns about the study or the way it is conducted or if you want to complain about any aspect of this study, please contact Professor Andrew Gumley, Mental Health and Wellbeing, Gartnavel Royal Hospital, 1st Floor, Admin Building, University of Glasgow, Glasgow G12 0XH. Tel: 0141 211 3920.

The normal NHS complaint mechanisms will also be available to you. If you wish to make a formal complaint about any part of the care provided to you as a participant in a research project, you can contact your local NHS complaints team.

**Can I speak to someone who is not involved in the study?**

Yes you can. Dr Hamish McLeod who is not involved in the study can answer questions or give advice about participating in this study. His telephone number is 0141 211 3927.

**What do I do now?**

If you are interested in taking part in the study, please complete the slip overleaf and give it to a member of the staff team who will return it to me. Alternatively you can contact me directly using the contact details below. I will then contact you to answer any questions that you may have about the study and arrange an appointment for the interview.

**Contact Details**

Chief Investigator:
Fiona Scott
Trainee Clinical Psychologist
Dept of Psychological Medicine,
Administration Building,
Gartnavel Hospital,
1055 Great Western Road,
Glasgow
G12 0XH
Email: f.scott.2@research.gla.ac.uk
Tel: 07951890858

Academic Supervisor:
Professor Andrew Gumley
Professor in Clinical Psychology
Dept of Psychological Medicine,
Administration Building,
Gartnavel Hospital,
1055 Great Western Road,
Glasgow
G12 0XH
Tel: 0141 211 3920

Thank you very much for reading this and for any further involvement you may have with the study.
Appendix 7 - Staff Information Sheet

STAFF INFORMATION SHEET (Version 2.0, 11/11/2016)

Title of the Study: What's it like having a son or daughter in Forensic Mental Health Services? An Interpretative Phenomenological Analysis of mothers’ experiences

Researcher: Fiona Scott

This information sheet has been given to you as a clinician in the Forensic Mental Health Team in Lanarkshire, or as a member of staff at Support in Mind Scotland. I would like to ask you to take a few minutes of your time to read over this information sheet.

This sheet is designed to give you all the information that you will require to understand the study and identify individuals who may want to participate. I have tried to answer any obvious questions that you may have, but if you would like to discuss any aspect of the study further, please do not hesitate to contact me.

Background and Purpose

I am training to be a Clinical Psychologist and am a postgraduate student at the University of Glasgow. I also work within NHS Lanarkshire as a Trainee Clinical Psychologist. As part of my training I am conducting this research project to help gain a better understanding of mothers’ experiences of caregiving in a forensic context.

What is the study about?

The aim of the study is to investigate the experiences of caregiving from the perspective of mothers of forensic mental health patients, specifically how they have made sense of their experiences, roles and relationships.

Who is eligible to take part?

Inclusion Criteria:

- Mothers of a patient, of NHS Boards Forensic Mental Health Teams or Mothers who are in contact with Support in Mind Scotland who have a son or daughter, seen in Forensic Mental Health Services.
- Fluent in English (due to interviewer and interpreter constraints).

Exclusion Criteria:

- Mother has active psychotic symptoms
• Where there are known Health and Safety risks associated with the mother e.g. problematic substance misuse giving rise to erratic or impulsive behaviour.
• Mother is no longer in contact with the associated family member.

**What do I need to do?**

If you know of an individual who meets the criteria for the study, please provide them with the enclosed participant information sheet. If the individual is interested in participating, please ask them to complete the tear off slip provided and return it to me. Alternatively, they can contact me directly using the details at the bottom of the participant information sheet. I will then arrange an appointment at a convenient time and at an NHS or community location near where they live. When we meet I will ask them to sign a consent form to show that they have read and understood the information provided to them and that they agree to take part in the study.

**Do people have to take part?**

No, individuals do not have to take part and deciding not to take part will not affect them or the care of their relative in any way. Even if they do decide to take part, they can withdraw from the study at any point if they change their mind.

**What will happen to the participant information?**

The interviews will be recorded. The recordings will be transcribed, anonymised then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisors and I will have access to the recordings. The information will be analysed and presented in the form of a report and submitted to the University of Glasgow in part fulfilment of my Doctorate in Clinical Psychology and for publication in a scientific journal. Within the report, anonymous quotes of what participants have said may be used. Participants will be provided with a summary of the results if they wish.

**Are there any benefits to participants taking part?**

There are no direct benefits to the participant for taking part in this study. However, the information that is provided may contribute to our understanding of mothers’ experiences of caregiving within a forensic context. If this study is published in a scientific journal, it would contribute to the wider research literature and could contribute to developments in the psychological care and support of patients and families seen within forensic services.

**Are there any down sides to participants taking part?**

It is possible that the discussions may trigger upsetting thoughts of feelings that may be difficult for the participant to talk about. If this is the case, and the participant wishes to stop, they can end the interview at any time. If they do become upset, they will be signposted to relevant supportive
services. Participants can also choose to be contacted one week following the interview in order to discuss any questions or concerns they may have.

**Who has reviewed the study?**

The study has been reviewed by the University of Glasgow and the West of Scotland Research Ethics Committee to ensure that it meets standards of ethical conduct. Approval has been granted by NHS Lanarkshire Research and Development department.

**What if something goes wrong?**

If you have any concerns about the study or the way it is conducted or if you want to complain about any aspect of this study, please contact Professor Andrew Gumley, Mental Health and Wellbeing, Gartnervle Royal Hospital, 1st Floor, Admin Building, University of Glasgow, Glasgow G12 0XH. Tel: 0141 211 3920.

**Contact Details**

Chief Investigator: Fiona Scott
Trainee Clinical Psychologist
Dept of Psychological Medicine,
Administration Building,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow
G12 0XH
Email: f.scott.2@research.gla.ac.uk
Tel: 07951890858

Supervisor: Professor Andrew Gumley
Professor in Clinical Psychology
Dept of Psychological Medicine,
Administration Building,
Gartnavel Royal Hospital,
1055 Great Western Road,
Glasgow
G12 0XH
Tel: 0141 211 3920

Thank you very much for reading this and for any further involvement you may have with the study.
Appendix 8 - Recruitment Poster

Recruitment Poster NHS (Version 1.0, 29/07/2016)

Are you the mother of someone supported by Forensic Mental Health Services?

We want to interview mothers as part of a research project to better understand what it is like to be a carer for a son or daughter who is supported by Forensic Mental Health Services.

We hope that this will help ensure that carers’ perspectives are part of service provision.

**What will I have to do?** Interviews will take approximately 1 hour and will be conducted in an NHS or community location near where you live.

If you are interested or would like further information, please speak to a member of the Forensic Mental Health Team or alternatively contact: Fiona Scott - 07951890858 or email f.scott.2@research.gla.ac.uk
Appendix 9 - Participant Consent Form

CONSENT FORM

(Version 3.0, 27/01/2017)

Title of Project: What’s it like having a son or daughter in Forensic Mental Health Services?

Name of Researcher: Fiona Scott

1. I confirm that I have read and understand the information sheet (Version 2.0, 11/11/2016) for the above study and have had the opportunity to ask questions, and am satisfied with the answers I received.

2. I understand that my participation is voluntary and that I am free to withdraw at any time. Should I wish to withdraw, I understand that I can do so without giving reason, and without my legal rights being affected and without my family members care being affected.

3. I understand that all my information will be kept confidential and that only the researcher and her supervisors will have access to that information.

4. I agree to my interview being audio recorded and transcribed

5. I agree that fully anonymised quotations may be used in the study write up, publications and other materials arising from the study, but that these will be fully anonymised and it will not be possible to identify myself or my family member as an individual.

6. I agree to take part in the above study.

If, when the study is finished, you would like to receive a short summary of the study findings please write your postal address below.

______________________  _________________  __________________
Name of Participant   Date                     Signature

______________________  _________________  __________________
Name of Person taking consent  Date  Signature
(if different from researcher)

______________________  _________________  __________________
Researcher  Date  Signature
Appendix 10 - Interview Schedule

Interview Schedule (Version 2.0, 11/11/2016)

This is a semi-structured interview, so not all questions may need to be asked. These are more like prompts to help the interviewer and participant. The interviews may take different directions depending on what the participant brings.

General Strategy

- Engaging
- Supportive
- Permits Exploration
- Don’t impose pre conceptions
- Enable individual to reflect on their experiences

Introduction

“Thank you for agreeing to attend this interview today, I really appreciate you giving up your time to speak to me about your experiences of caregiving. Just before we start, I’d like to go over a few bits of paperwork. Firstly, I just need to make sure that you know why you have come along today and that you are still ok to go ahead with the interview. Did you understand everything in the Participant Information Sheet? (If no, clarify information, if yes present consent form) Then I would just like to go through this consent form with you. If you agree with the statements listed, then initial the box next to it. Once you are finished, sign the bottom of the page”.

“Today I am going to be asking you some questions. If there are any you don’t want to answer, that is okay. If you want a break at any time, that is fine also. Finally, if you want to stop at any time do just let me know”.

Section 1) Overview

1) Could you give me an overview of your family situation….who is in it
2) Can you tell me about your relationship with (index person)

Section 2) Core experiences around person becoming unwell/involvement with forensic services/ impact on the person

3) When did (index person) first become unwell?
4) What led (index person) to come into forensic mental health services?
5) What impact has this had on you (i.e. the index person being involved with forensic services)?
6) How did this change your relationship with (index person)?
7) How did this affect how you feel/felt as a mother/ your role as a mother? Have you made sense of this? / How did you make sense of this in relation to your role as a mother?

8) What impact has this had on your wider family?

Section 3) Support as a mother.

9) Have you received help and support in relation to these experiences? (probe around health and other services)

10) What do you think would have been helpful for you or others in your position?

Section 4) Moving forward to the here and now.

11) How has your relationship with (index person) changed over time (from first involvement with services to now)

12) How would you describe your relationship with (index person) today?

13) Given your experiences, how would you like things to be different for (index person) and you, in terms of your relationship?

14) Finally is there anything else that you’d like to add to what we’ve already discussed?

15) Is there a question you hoped I’d ask and didn’t?

“That is the end of the interview. Thank you very much for coming along today and talking about your experiences. What will happen now is that I will analyse the data and produce a report. It will all be anonymous and if you have said on your consent form that you would like a copy, I will send you one when it’s finished.

Finally, sometimes people can find talking about their experiences makes them have mixed feelings. It may stir up old thoughts and feelings. This is normal after talking about your experiences, and will pass.

If you wish, I will contact you by telephone in one week so that you may have the opportunity to discuss any questions or concerns you may have about this interview process. If you think that you need further support about what we have discussed, I can give you information about relevant support services. Thank you for your participation”.

Participant wishes to be contacted in one week   Yes / No
<table>
<thead>
<tr>
<th>Themes</th>
<th>Original Transcript</th>
<th>Exploratory Comments</th>
</tr>
</thead>
</table>
| Excellent relationship        | Good good, its good you’ve got alot of contact. How would you describe your relationship with [son]?
I would say at this moment in time, excellent **Good**
As best it could really be at this point em, because obviously he’s clean of drugs and he’s had more time to think about, reflect on what, what’s unfolded in the last couple of years and eh I think the help he’s had obviously from being in [secure ward 3] and then in [secure ward 2] and now [secure ward] I think it’s given him time to really reevaluate his life and where he’s goin so I think everything is pretty positive just now. **Good, good. So you feel like that time for him has given your relationship a chance to develop, would you say?**
Ye I’ve always had a good relationship with [son] up until the last few years when well obviously not so much since he went into the mental health system but obviously it wasn’t great as in he was goin out and **doing crazy stuff** things that were a **big worry for me**. Worry he was going to kill himself if he was driving you know but he was caught with the car but he hadn’t been drinking or anything like that so that was one thing I thought well at least he wasn’t daft enough to be drinking, not that he should be driving without a licence but anyway em ye but I would say [son] probably out of my three children I’ve probably got the best relationship with. **Ah ok**
And its not because he’s the baby (laughs), he’s just quite em quite a nice young man you know **now that he’s back to himself** and I’m not just saying that because, i’ve never, when he was | Excellent relationship with son at the moment
Best it could be due to him not being on drugs
**Making sense of their positive relationship due to son being off drugs, having time to reflect/reevaluate life-being within secure hospital**
Always had a good relationship until a few years ago when son did things that worried her and was involved with MH system.
**Mental health problems affected their relationship??**
**Crazy stuff- making no sense to her Anxiety**
Worried he’d kill himself driving
Driving offences
Best relationship now out of her three children
Positive attributes of son now – nice young man
**Son is back as if he went away**
Describing positive attribute of son in past |
<table>
<thead>
<tr>
<th>Searching for answers/trying to make sense of sons behaviours/uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>twelve and we were out in Australia for a while staying at my sister’s house and em I says to her quite knaiviely when he was twelve, I says I’m never gonna have any bother with that boy, he’s great, and. I mean thats how good he was. Ye, that was your impression</td>
</tr>
<tr>
<td>Then just obviously these last few years when he’s went down badly. And I found out he was taking cocaine when he was fifteen. But I only found that out years later. Em, cos he was, he did go through a phase of like having really bad tantrums and I just thought he had an anger issue and something was bothering him. But I later found out, years later it was the cocaine he was taking and he was maybe coming off of it or whatever it was doing to his head. Yep, yep absolutely</td>
</tr>
<tr>
<td>Ye but I mean it just, it might have been naive for me to think that oh he was just having a bad time, difficulty you know dealing with things you know I guess that’s quite understandable, you know</td>
</tr>
<tr>
<td>Ye I mean I’d never reckon for a minute that he’d be going the pathway and goin out the door and going and taking cocaine. I think I dunno how that happens. You know, I really don’t cos. Its never been my lifestyle, you know.</td>
</tr>
<tr>
<td>Good relationship now</td>
</tr>
<tr>
<td>In what way- in her estimations???</td>
</tr>
<tr>
<td>Change in son in last few years</td>
</tr>
<tr>
<td>Discovery of drug use as a teenager</td>
</tr>
<tr>
<td>Attributed tantrums to anger issues rather than effects of drugs</td>
</tr>
<tr>
<td>Doubting/questioning self/uncertain</td>
</tr>
<tr>
<td>Self as not knowing/should have known/blame/judging self</td>
</tr>
<tr>
<td>Reflecting on past thoughts</td>
</tr>
<tr>
<td>Never thought her son would be taking cocaine</td>
</tr>
<tr>
<td>Contrary to her beliefs about son</td>
</tr>
<tr>
<td>Questioning/uncertainty/disbelief???</td>
</tr>
<tr>
<td>Searching for how this happened as it goes against her lifestyle</td>
</tr>
</tbody>
</table>
## Appendix 12 - Sample Themes and Exemplars

<table>
<thead>
<tr>
<th>Superordinate Themes</th>
<th>Subthemes</th>
<th>Exemplars</th>
<th>Representation</th>
</tr>
</thead>
</table>
| Negotiating the conflict between vulnerability and threat | “I feared for his life” - Son as vulnerable | **Judith**
*Interviewer: “That must have been really really hard considering how close you were?”*
Judith: “Then one night he said he was going to kill his self. He came down and he said, mum, there’s something in my head and it’s making noises and that and I can’t handle this. Then he was out in the garden and screaming and holding his head”.

| Judith | Interviewer: “They told us that form that [son] had was a rare form of Schizophrenia.”
Judith: “and they normally don’t come though the other end.” | Judith
| Claire | Interviewer: “The GP you posted it to?”
Claire: “Yes, his GP and the social worker. And I says I desperately need help, [son] desperately needs help. I says his life could be a risk if he doesnae get the help he needs.” | Claire
| Maria | Interviewer: “Em, you were talking about, ye I was asking you about your role. You said it was heartbreaking as you try to do your best.”
Claire: “I worried constantly and I went to my sister, she’s a social worker, I went to her for advice. She says I seen [son], he’s lost alot of weight and this and that. Em I could see he wasnae right, he wasnae well.” | Anne
| Anne | | Susan |
Claire
Interviewer: “Oh dear”
Claire: “That frightened me.”
Interviewer: “Oh absolutely. So what did you do?”
Claire “So after that I thought, he’s gonna get killed. Somebody’s going to attack him.”
Interviewer: “That must have been really scary.”
Claire: “I feared for his life actually”

Maria
Maria....... “And I mean he was just coming home with so many injuries you know. It was just horrific.”

Maria
Maria..... “And fortunately he was with someone who had the common sense to call an ambulance. So that’s how he ended up in the actual hospital or he would have died with blood loss.”

Maria
Maria..... “Not knowing whether he was alive or dead or you know.”

Maria
Maria... “Worry he was going to kill himself if he was driving you know.”

Anne
Anne..... “But at the end of it em, the CPN, whats his name,[cpn]. He em, spoke, He’s the only one that spoke for [son], saying that, you know, that the illness was overtaking him at the time.”

Anne
Anne...... “you no going to go and see a Doctor or something.”

Anne
Anne..... “And he didnae have the medication with him. Look, I says, I felt, the way he was was bad enough, it was going to get ten times worse, if he’s no getting the medication or nothing.”

Susan
Susan..... “and I said but I can’t leave him, he’s really really ill (tearful). I said and I’ll need to get him to hospital.”

Susan
Susan..... “Oh he phoned me from Spain, oh you need to get me money, you need to send me money. And he was high, I could tell he was high, high and I, you know I was worried sick then.”

Susan
Susan..... “And he had been back seeing his CPN and he was, he was taking the medication again because he was feeling a bit unwell but he was still as far as I know he was drinking, but not, I don’t know how much because this was in[city] . And eh, he had to come home because he was frightened when he was doing things, you know the windows or whatever and I dunno if he was working on roofs as well but he came home and he was clearly unwell.”

Susan
Interviewer: “It must have been a terrible shock. So did you see him in [prison].”
Susan: “Yes, yes, we went to see him every day.”
Interviewer: “And how was that?”
Susan: “Oh, I mean, that was just.. he was a poor soul, he was just a poor poor soul. There was no doubt about that.”
Appendix 13– Major Research Proposal
Major Research Project Proposal

Abstract

Background
People using forensic mental health services often have complex difficulties and the impact of these on carers is an area requiring further investigation. Expressed Emotion (EE) was a term developed to give a measure of the emotional atmosphere of an individual’s home environment and is now well established as a predictor of relapse. Less is known about the processes underlying EE; however, it has been suggested that there are a number of factors that may influence the expression of different patterns of EE. Given the complexity of these relationships and the limited literature regarding forensic contexts, a qualitative approach appears to be merited.

Aim
To investigate the experiences of caregiving from the perspective of mothers of forensic mental health patients, specifically how they have made sense of their experiences, roles and relationships.

Methods
Interpretative Phenomenological Analysis (IPA) methodology will be employed. Participants will be recruited from local NHS community forensic mental health services and the mental health charity Support in Mind Scotland. Participants will be interviewed in order to gain an understanding of their experiences of caregiving. Data will be transcribed and subsequently analysed using IPA methodology.

Applications
A more in depth knowledge and understanding of caregiving within forensic contexts could mean that this important influence could be better integrated into both individual and family approaches to recovery.
Introduction

People using forensic mental health services often have complex difficulties, substantial service needs (Phipps, 1994), and a disproportionate number of mental health problems (Keene, 2001; Singleton & Meltzer, 1998). The prevalence of psychosis in individuals within the criminal justice system is estimated to be twenty times that of the general population (Joint Commissioning Panel for Mental Health, 2013). It is important to consider the impact that these problems may have on the relatives and carers of these individuals. Studies of carers of individuals suffering from serious mental health problems, such as psychosis reveal high levels of psychological distress, including anxiety and depression, as well as economic strain, reduced quality of life and stigmatization (Martens & Addington, 2001; Scazufca, Kuipers, & Menezes, 2001; Tennakoon et al., 2000; Treasure et al., 2001). However the experiences of caregiving in families of forensic mental health patients is an area that has been seriously neglected (Tsang, 2000).

Expressed Emotion

Family and systemic approaches have widespread empirical support in the treatment of psychosis (Falloon, 2003). The focus on systemic approaches came from early findings that the family environment had a profound effect on rates of relapse (Brown, Carstairs and Topping 1958). Brown, Monck, Carstairs and Wing (1962) described five components of the family environment: critical comments (CC), hostility, emotional over involvement (EOI), positive remarks, and warmth. The combination of these five components gave a measure of what became known as Expressed Emotion (EE). Through interviews with family members and the consideration of these factors, families were categorised as being high or low in EE. High expressed emotion was associated with higher rates of relapse (Brown et al 1962; Brown, Birley and Wing 1972). The importance of expressed emotion (EE) as a measurement construct and as a robust predictor of relapse in schizophrenia has since been clearly established (Butzlaff & Hooley, 1998). Less is known however, about the experiences of being a relative or carer for an individual supported by forensic mental health services and specifically, how this may influence caregiving.

EE Processes

When considering the processes that are involved with EE, high EE has been linked to greater family burden (Patterson, Birchwood and Cochrane 2005). In addition, higher criticism has been associated with more personalising and controlling attributions for individual’s behaviours and symptoms by relatives (Patterson et al 2005). One factor that is
often described within EE literature, is the sense of loss that is felt by carers of individuals with psychosis. Patterson et al (2005) found that EE was unstable in early psychosis and that this instability was related to carers’ feelings of loss for their loved one. Greater loss preceded the development of higher levels of criticism and emotional over involvement. They concluded that EOI and criticism may be seen as adaptive reactions to perceived loss. Further to this, they suggest that loss may be perceived in relation to loss of cherished roles, goals or relationships associated with the unwell family member.

**The Attachment System**

Consideration of the attachment and caregiving systems of a parent and child dyad may help us to understand more about the underlying mechanisms of EE and loss. Patterson et al (2005) hypothesised that the perception of loss that is brought about by a relative experiencing a psychotic illness can trigger the attachment system of the caregivers and that this may bring about the thoughts, feelings and behaviours linked to expressions of criticism. The caregiver is thought to be trying to “restore the status quo” (a reaction to perceptions of loss; Patterson et al 2005, pg 62) in order to reduce distress and return things back to the way they had been previously. Patterson et al (2000, 2005) specify that the caregiver’s attachment system is implicated in this. However, it might be argued that it is the caregiving system that is more readily involved.

**The Caregiving System**

Bowlby (1969, 1980, 1988), as well as describing the attachment system, was first to describe the caregiving system. This was proposed as a system of organised behaviour shown by an attachment figure towards their child. It has been described as an evolved system, which is distinct from, but reciprocal to, the attachment system (Solomon and George 1996), which functions to provide protection (Solomon and George 1996; George and Solomon 1996; George and Solomon 2008). Under normal circumstances, threats activate the infant’s attachment system and they seek and move towards their attachment figure for protection. Similarly, when a caregiver detects danger, the caregiving system is activated and they move towards the infant to provide protection.

This system is required to work in harmony with other motivational systems. Parents are also caregivers to other children, a friend, a sexual partner, a worker and a person who seeks care from their own attachment figures (Solomon and George 1996; George and Solomon 2008). Solomon and George (1996) have suggested that the parent must be able
to create a balance of these competing demands, namely protection of her young and pursuit of other goals. In addition to this they suggest that the ability to be flexible with these can influence attunement, sensitivity and caregiving behaviours.

**Caregiving, Psychosis and the forensic context**

As can be seen, a number of different hypotheses have been proposed to explain the nature and quality of interactions between individuals and their families. Much of this evidence has come from studies utilising quantitative methodologies with individuals with a diagnosis of psychosis, who do not have a forensic history (Barrowclough & Hooley, 2003; Grice et al., 2009; Raune, Kuipers, & Bebbington, 2004; Barrowclough & Parle, 1997; Scazufca & Kuipers, 1999, Barrowclough, Lobban, Hatton, & Quinn, 2001, Kuipers, Onwumere, & Bebbington, 2010). Less is known about the experiences of caregiving in the context of forensic mental health. In a forensic context there may be commonalities, such as symptoms of psychosis, but there may be additional layers of complexity arising from the individual’s offending behaviour that have led to involvement of forensic services. This factor may also impact upon caregiving and by extension the quality of interactions and support. Having a better understanding of caregiving within a forensic context will further enable the development of methods to support the needs of care providers.

There have been very few studies conducted specifically to investigate family carers’ experiences of caring for a relative supported within a forensic context (Ridley, McKeown, & Machin, et al., 2014; Canning, O’Reilly, Wressell, Cannon & Walker, 2009; MaclInnes, Beer, Reynolds & Kinane, 2013). Nordstrom, Kullgren & Dahlgren (2006) conducted a qualitative study to investigate parents’ experiences of caring for their adult sons who were seen in forensic mental health services due to psychosis and a history of violent offending. Using grounded theory, they constructed four key themes for parents around onset of mental disorder, diagnosis of schizophrenia, violent behaviour/criminality and referral to forensic psychiatric treatment. These experiences were found to illicit emotional reactions such as guilt, fear, disappointment, anger and relief, which in return led to different actions taken. These included searching for causes, searching for information, staying ignorant, distancing, blaming others, hoping for the future and transferring responsibility. In a review by Tsang, Pearson and Yuen (2002) examined the needs and burdens of mentally ill offenders (James 1996; McCann, 1993; McCann and McKeown, 1995; McCann, McKeown & Porter, 1996). They have suggested that the relatives of offenders with mental illness experience more stress than those of patients who do not have an offending
history. When they examined the factors leading to the additional stress and burden, they found that the former group of relatives experienced additional stigma related to the criminal offence, and a need to cope with legal proceedings and concerns regarding violence.

**Rationale for this study**

There is a need for further research exploring the experiences of carers in a forensic context. Improving our understanding of forensic caregiving could help us to develop interventions that have a greater consideration of caregiving experiences. This in turn may help in the development of appropriate services, which may improve the wellbeing of both patients and carers. Qualitative methodology will be used to facilitate a greater understanding of mothers’ experiences of caregiving within a forensic context. The exploration of mothers’ experiences in particular has been chosen, as much of the attachment literature has focussed on mother and child interactions and relationships. It was felt that this relationship would be most pertinent in this study due to the potential influences of attachment and caregiving processes. Interpretative Phenomenological Analysis (IPA) is a qualitative approach, which aims to explore how people make sense of their world and their experiences (Smith & Osborn, 2008). IPA allows for an in depth description of experiences, which can be interpreted into different themes. The themes can then help us to understand in more detail the responses, relationships, roles and experiences of the individual. The intention is not to propose a full theory but to develop an understanding of an experience, linked to current research with clinical implications (Smith, 2004). Given the substantial service needs of individuals and family members supported within forensic mental health services, this is an area that warrants further investigation. One of the strengths of IPA is in its application to smaller homogeneous samples such as those potential participants to be recruited to the current study.

**Aim**

To investigate the experiences of caregiving from the perspective of mothers of patients supported within the forensic mental health system, specifically how they have made sense of their experiences, roles and relationships.

**Plan of Investigation**

**Design**- The project will utilise Interpretative Phenomenological Analysis (IPA). IPA explores how individuals make sense of their personal and social world, with a focus on finding the meanings that are attached to specific experiences (Smith & Osborn, 2008).
Given the focus of this project, it seems an appropriate tool for use to interpret semi-structured interviews designed to explore individuals’ personal experiences of caregiving and to understand and interpret what these experiences have meant from the participants’ perspective.

**Participants:** Purposive homogeneous sampling will be utilised such that participants will be selected due to their experiences of caregiving and the in-depth insight they can provide into these experiences.

Inclusion Criteria:

- Mothers of a patient, of NHS Boards Forensic Mental Health Teams or Mothers who are in contact with Support in Mind Scotland who have a son or daughter, seen in Forensic Mental Health Services.
- Fluent in English (due to interviewer and interpreter constraints),

Exclusion Criteria:

- Mother has active psychotic symptoms
- Where there are known Health and Safety risks associated with the mother, e.g. problematic substance misuse giving rise to erratic or impulsive behaviour.
- Mother is no longer in contact with the associated family member.

**Recruitment Procedures:** Participants will be identified via carer groups and staff of NHS Forensic Mental Health Services, as well as from the mental health charity Support in Mind Scotland. Posters and leaflets about the study will be made available within NHS boards Forensic Mental Health Team premises. Information will also be circulated in relevant local NHS carer newsletters and bulletins if these are available. Staff will be given information about the study and encouraged to identify suitable participants and provide them with the Participant Information Sheet. In addition, permission will be sought for the researcher to visit the carer groups and deliver a short presentation about the study. The participant information sheet will be left for those interested in finding out more about the study. This will contain contact details of the researcher. Those interested in participating will be asked to complete a slip containing their contact details. This can then either be posted to the researcher or can be given to the staff member who can return it to the researcher. Alternatively, the potential participant can contact the researcher directly. The researcher will then contact the person and if still interested in participating, a meeting will be arranged. The researcher will meet with potential participants at local NHS and
community venues. Written informed consent to participate will be obtained. The semi-structured interview will then be completed.

**Potential Measures:**
Semi-structured Interview regarding individuals’ experiences of caregiving-

See appendix/attached documents

**Research Procedures**- People who meet the inclusion criteria and who consent to take part in the study will participate in a semi-structured interview lasting around 1 hour. Participants can choose if they wish to be contacted one week after the interview to discuss any concerns or ask any questions they may have about the interview. If required, participants will be signposted to relevant sources of support.

**Data Analysis**- The interviews will be recorded, transcribed verbatim and anonymised, with patient and participant identifying information removed. Once satisfactorily transcribed, recordings will be deleted. IPA protocols will be employed and transcripts analysed following the recommended procedures. Data will be organised and analysed using NVivo software. Once themes within the data have been identified by the researcher, a reliability check will be carried out by the researcher’s supervisors. Additionally, a reference group of individuals with caregiving experience from Support in Mind Scotland will be utilised to provide comments on the themes identified, in order to validate the findings and provide a credibility check. Any analysed data will be anonymised such that neither the participant nor their family member will be identifiable.

**Justification of sample size** – Due to the project having a purposive rather than a generalisability approach, with the aim of gaining a thorough understanding of participants’ experiences of caregiving, the sample will be a closely defined group, chosen in order to increase homogeneity of perspectives. Braun and Clarke (2013) have suggested that sample sizes should be adequate to ensure there is enough data to develop a rich story yet not too much that time and resources limit a deeper analysis of the data. Sample size will also be dependent on the methods of data collection (Braun and Clarke 2013). Given that this project will utilise semi-structured interviews that will yield rich data, a sample size of 10-12 should be adequate.
Settings and Equipment – Individual interviews will be conducted within available private rooms in local NHS and community premises with clearly defined procedures in place to ensure safety of participant and researcher. Interviews will be recorded on an encrypted digital audio/voice recorder.

Health and Safety Issues

Researcher Safety Issues: The researcher will follow all local health and safety procedures, e.g. sign in/out book. A mobile phone will be carried at all times in case of emergencies and a call in safe system will be utilised. Interviews will be carried out within normal working hours and abide by the standard NHS guidelines for interviewing patients.

Participant Safety Issues: Some of the experiences that are discussed may be difficult for the participants to talk about and there is a risk that they may become distressed. This will be highlighted in the Participant Information Sheet. If a participant does become upset or an unmet need is discovered, the researcher will attempt to comfort the participant, cease questioning if required and stay with the participant until their distress decreases. The researcher will signpost the participant to sources of support. In order that participants are not overwhelmed, the interview will be split into two sessions if required. Participants will be asked if they wish to be contacted by the researcher one week following the interview. This will be done in order to give participants the opportunity to discuss any concerns or ask questions they may have about the interview process. If required, the researcher will signpost the participant to relevant sources of support.

Ethical Issues: All relevant ethical approval will be sought from relevant research ethics committees before any participants are approached. The project will also be registered with relevant NHS Boards’ Research and Development Departments. Data will be stored and eventually destroyed after 10 years in accordance with the Data Protection Act (1998) as well as NHS and University of Glasgow policies.

Written informed consent will be obtained before the interviews take place. Participants will be informed that they may withdraw from the study at any time. Participants will also be informed about confidentiality and its limits. The Participant Information Sheet will state that some of the experiences may be highly emotive and difficult to talk about for some individuals. Consent will also be sought for the use of verbatim anonymised quotations to be used within the final written report. It will be made clear to potential participants that all details will be fully anonymised and that their identity or the identity of
their son or daughter will not be detectable from the use of quotations. Any identifiable information, e.g. participant names with associated participant identification numbers will be kept in a locked filing cabinet within the Institute of Mental Health and Wellbeing, Gartnavel Royal Hospital. The recordings from the interview will be transcribed, made anonymous and then destroyed. The anonymous transcripts will be stored on an encrypted password protected computer.

**Financial Issues** – Equipment costs will amount to an encrypted digital voice recorder and an encrypted laptop computer (to be borrowed from The University of Glasgow), subscription to Nvivo software and photocopying/printing costs.

**Timetable** –

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<thead>
<tr>
<th>Date</th>
<th>Task</th>
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<tbody>
<tr>
<td>May 2016</td>
<td>Proposal Submitted</td>
</tr>
<tr>
<td>June 2016</td>
<td>Approval Letter from Research Director</td>
</tr>
<tr>
<td>Late June 2016</td>
<td>Submit project for Ethical Approval</td>
</tr>
<tr>
<td>September 2016</td>
<td>Hope to receive Ethical Approval</td>
</tr>
<tr>
<td>Mid September 2016</td>
<td>Commence Recruitment</td>
</tr>
<tr>
<td>March 2016</td>
<td>Complete Recruitment</td>
</tr>
<tr>
<td>March/April 2016</td>
<td>Analysis of Interviews</td>
</tr>
<tr>
<td>May 2016</td>
<td>Write up Research</td>
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<tr>
<td>July 2016</td>
<td>Submit Final Copy (Inc. Sys Review)</td>
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**Practical Applications**- There is substantial evidence that family approaches can influence outcome and relapse in mental health problems (Falloon, 2003). Having a better understanding of experiences of caregiving will be useful in terms of highlighting potential areas for intervention. It is hoped that this study will provide a greater insight into caregiving experiences, such that clinical formulations can be developed with the caregiving system and EE processes being made more explicit. This in turn could have implications in both individual and family treatment approaches and hence improve wellbeing and reduce relapse.
In addition, it is anticipated that this project begins to define the caregiving system for mothers of individuals seen within a forensic mental health setting. In future studies, this could be built upon such that it may be possible to develop a caregiving questionnaire. Having a well validated questionnaire measure could be used in future research and in clinical practice. When considering future research, an added benefit of having a more thorough understanding of the caregiving system could be that it develops our understanding of other clinical models, for example, the attribution model of relapse (Barrowclough, Johnston and Tarrier 1994).

References


