Caregivers’ Perspectives of their Relative’s Admission

Veronica F. Ranieri

This Thesis is submitted in fulfilment of the requirement of a Doctor in Philosophy at the University of Dublin, Trinity College Dublin, Ireland.

This research was conducted in the School of Psychology

September, 2015
Table of Contents

DECLARATION .............................................................................................................................. iv
Summary ....................................................................................................................................... v
Acknowledgements ...................................................................................................................... vii

Study One

Introduction ................................................................................................................................. 2
  1.1 The Irish Mental Health Act 2001 ....................................................................................... 2
    1.1.1 Involuntary Detention ................................................................................................. 2
    1.1.2 Informed Consent ........................................................................................................ 5
  1.2 Psychiatric Admissions in Ireland ....................................................................................... 5
  1.3 Coercion at Admission ....................................................................................................... 7
  1.4 Coercion and Perceived Coercion ..................................................................................... 9
  1.5 Service Users’ Perceptions of Coercion at Admission ...................................................... 10
  1.6 Coercion in Irish Psychiatric Admissions ......................................................................... 13
  1.7 Caregivers’ perceptions of coercion at admission ............................................................... 14

Literature Review ....................................................................................................................... 16
  2.1 Caregiving ......................................................................................................................... 16
  2.2 Using a Stress-Coping Theoretical Framework ................................................................. 18
  2.3 The present study ............................................................................................................. 32

Methodology ................................................................................................................................ 34
  3.1 Recruitment ....................................................................................................................... 34
  3.2 Procedure ........................................................................................................................ 36
  3.3 Participants ....................................................................................................................... 37
  3.4 Instruments ...................................................................................................................... 38
  3.5 Ethical Considerations .................................................................................................... 46
  3.6 Statistical Analysis .......................................................................................................... 46

Results ....................................................................................................................................... 48
  4.1 Initial Data Management .................................................................................................. 48
  4.2 Descriptive Analysis ....................................................................................................... 48
  4.3 Hypothesis Testing ......................................................................................................... 49

Discussion .................................................................................................................................. 71
  5.1 Summary of findings ....................................................................................................... 71
  5.2 Theoretical Model .......................................................................................................... 85
  5.3 Strengths and Limitations .............................................................................................. 86
  5.4 Directions for Future Research ...................................................................................... 88

Study Two

Introduction ................................................................................................................................. 91

Methodology ............................................................................................................................. 96
  7.1 Research Aims & Objectives ......................................................................................... 96
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.2</td>
<td>Theoretical Framework</td>
<td>96</td>
</tr>
<tr>
<td>7.3</td>
<td>Recruitment</td>
<td>97</td>
</tr>
<tr>
<td>7.4</td>
<td>Participants</td>
<td>97</td>
</tr>
<tr>
<td>7.5</td>
<td>Procedure</td>
<td>98</td>
</tr>
<tr>
<td>7.6</td>
<td>Instrument</td>
<td>99</td>
</tr>
<tr>
<td>7.7</td>
<td>Data Analysis</td>
<td>100</td>
</tr>
<tr>
<td>7.8</td>
<td>Reflexivity</td>
<td>101</td>
</tr>
<tr>
<td>7.9</td>
<td>Ethical Considerations</td>
<td>101</td>
</tr>
<tr>
<td>8.1</td>
<td>Experiences prior to admission</td>
<td>104</td>
</tr>
<tr>
<td>8.2</td>
<td>Experiences at Admission</td>
<td>108</td>
</tr>
<tr>
<td>8.3</td>
<td>Experiences of hospitalisation</td>
<td>113</td>
</tr>
<tr>
<td>8.4</td>
<td>Experiences following Discharge</td>
<td>116</td>
</tr>
<tr>
<td>9.1</td>
<td>Summary of Findings</td>
<td>124</td>
</tr>
<tr>
<td>9.2</td>
<td>Comparison with previous research</td>
<td>124</td>
</tr>
<tr>
<td>9.3</td>
<td>Implications</td>
<td>129</td>
</tr>
<tr>
<td>9.4</td>
<td>Strengths and Weaknesses</td>
<td>132</td>
</tr>
<tr>
<td>9.5</td>
<td>Future Research &amp; Education</td>
<td>134</td>
</tr>
<tr>
<td>10.1</td>
<td>Concluding Remarks</td>
<td>137</td>
</tr>
<tr>
<td></td>
<td>Part III:</td>
<td>139</td>
</tr>
<tr>
<td></td>
<td>References</td>
<td>140</td>
</tr>
<tr>
<td></td>
<td>Part IV:</td>
<td>153</td>
</tr>
<tr>
<td></td>
<td>APPENDICES</td>
<td>153</td>
</tr>
</tbody>
</table>
DECLARATION

This thesis is submitted as an exercise for a degree at this or any other University and is entirely my own work. I agree that the Library of Trinity College Dublin may lend or copy this thesis upon request.

______________________________________________

Veronica F. Ranieri
Summary

Caregivers often act as invisible pillars of support to both the service user and their adjoined mental health service. Caregiving can have a profound positive and negative effect on the caregiver’s health and relationship with their relative. In Ireland, approximately two-thirds of involuntary admission orders were submitted by a caregiver. However, to date, little is known about how caregivers experience their relative’s admission. This study set out to examine the caregiver’s perspective of the service user’s admission to psychiatric hospital. This thesis primarily focused on caregivers’ perceptions of coercion, pressures and procedural justice at admission and whether such perceptions were influenced by the service user’s legal status. It also addressed whether the constructs most frequently associated with caregiving: burden, psychological distress, expressed emotion and coping style, were linked to how caregivers perceived the admission. As caregivers' perceptions of caregiving and burden may affect both their care and their relative’s adherence to treatment and possibility of subsequent readmission, it is reasonable to question whether their perceptions surrounding the admission may also have an impact.

In this study, caregivers perceived the service user’s psychiatric admission as less coercive and more procedurally just than reported by service users. Perhaps surprisingly, caregivers of voluntarily admitted service users perceived the admission as more coerced and less procedurally just than caregivers of involuntarily admitted service users. Overall burden and psychological distress did not differ between caregivers. However, caregivers of those who were involuntarily admitted reported that they provided a higher level of supervision to their relative. When these key factors were entered into a regression model, we found that neither perceived coercion nor perceived pressures predicted burden or psychological distress in caregivers. Nonetheless, those who viewed the service user’s admission as more procedurally just were less burdened and distressed. Furthermore, a number of other hypotheses are suggested within the thesis.

Our findings may, therefore, indicate a need for caregivers and their relatives to share their experiences regarding the admission and instill their preferences for possible future admissions by means of advance directives. Furthermore, caregiver psychoeducation that
focuses on reducing expressed emotion and the use of maladaptive coping skills may help improve caregivers’ ability to care and reduce the incidence of readmission.
Acknowledgements

It really took a village to complete this thesis! I am incredibly grateful and thankful to all those who have helped along the way.

Special mentions must go out to the following:

Dr. Brian O'Donoghue: The creator of the original Service User Perspectives of Admission study who co-designed and co-analysed the quantitative study and facilitated our partnership with NUI Galway's team of researchers. Thank you Brian for your vast patience and relentless energy.

Mr. Kevin Madigan: Co-designer of the quantitative study, day-to-day project co-coordinator, recruiter and continuous source of support. Thank you for imparting me with your wisdom (on research, human relations and life), ideas and banter over the years.

Dr. Charlotte Wilson: Supervisor and source of encouragement. I know you entered this study quite late in the day, however, thank you thank you thank you! You have helped restore my shattered confidence. I am so grateful to you for reading my many, many drafts and for being, most of all, human.

Prof. Larry Davidson: Co-facilitator of the qualitative study. Thank you for providing me with the opportunity to learn from you and your team at Yale PRCH. I feel so lucky to have witnessed your work and met your wonderful team. Pigs do fly… Thank you also for sharing your wisdom and humour with me over Archie Moore’s.

Thank you to the wonderful team at Galway University Hospital: Prof. Colm McDonald, Dr. Brian Hallahan, Dr. Emma Bainbridge and David McGuinness. I am indebted to your kindness and support in letting me team up with you. Brian, thank you for your words of encouragement and for your help with day-to-day project management. David and Emma, thank you for your immense help with recruitment.
To the wonderful team at St. John of God Hospital and Newcastle Hospital: Dr. Eric Roche, & Dr. Larkin Feeney: thank you for your help in getting the study off the ground. Eric, thank you for your help in recruiting caregivers to our cause and for your words of encouragement.

To my appraisers, Ms. Barbara Hannigan and Dr. Michael Gordon, thank you for your astute insight and advice over the three years.

To Juliana Onwumere, my external examiner, thank you for helping me improve this thesis. Your advice and direction were truly needed and valued.

To my family, thank you for your unwavering support and affection. I love you all.

To those I shared many laughs, tears, beers and hugs with over these few years: Emily, Farzad, Georgia, Kristin, Margo, Maria, Nora, Patrick, Sinead and Tiziana: thank your friendship. I miss you!

Ian: You have been my rock through thick and thin. Thank you for being the bestest friend there is. I promise I will now stop talking about the PhD.

To my other two partners in crime, Sinead and Dee, thank you for the laughs and for accepting me as who I am from the very start. I believe it is now your turn to rant…
This study would not have been possible without the support of the Government of Ireland Postgraduate Scholarship, Mental Health Commission, Trinity College Dublin Studentship and Trinity College Dublin Graduate Travel Fund. Thank you.
Finally, thank you to all the families who shared their experiences with me and showed me what true strength is. This thesis is dedicated to you.
Part I:

Quantitative examination of caregivers’ perspective of the service user’s admission to an acute mental health unit

Chapter One: Introduction
Chapter Two: Literature Review
Chapter Three: Methods
Chapter Four: Results
Chapter Five: Discussion
Chapter One

Introduction

This thesis examines caregivers’ experiences of their relative’s admission to a psychiatric hospital. Although it will focus primarily on the caregiver’s perspective of the admission, it will also explore how caregivers experience their relative’s mental illness. As the majority of the caregivers’ perspectives were based on their experiences of their relative’s involuntary admission, this introduction will firstly describe how involuntary admission legally occurs in Ireland. This chapter will then detail the prevalence of involuntary and voluntary psychiatric admissions in Ireland. Finally, this chapter will outline the literature on coercion and perceived coercion at admission in service users and perceived coercion at admission in caregivers.

1.1 The Irish Mental Health Act 2001

The implementation of the Irish Mental Health Act (2001) led to significant changes in the process of hospital admission for both patients and caregivers. The act focuses on the involuntary admission and treatment of individuals who have a mental disorder, and the provision and upholding of an appropriate standard of care within the mental health services. The act is divided into the following six segments: preliminary and general information, involuntary admission of persons to approved centres, independent review of detention, consent to treatment, approved centres and miscellaneous. For the purpose of this doctorate, the second and fourth elements of this mental health act will be discussed as these are most relevant to the topic of perceived coercion.

1.1.1 Involuntary Detention

In Ireland a person may only be detained involuntarily in an approved mental health unit if he or she is found to be suffering from a mental disorder (Mental Health Act, 2001). The person cannot be involuntarily admitted on the grounds of a personality disorder, drug addiction or intoxication, or social deviance alone. In order for an individual to be initially involuntarily
admitted, the individual in question must be examined and referred onto the appropriate services in the following way:

a) An application for an involuntary admission must be made within 48 hours of observing the person. This application normally requires the completion of a form by a relative or spouse of the individual (Form 1), an ‘authorised’ officer “of a health board who is of a prescribed rank or grade and who is authorised by the chief executive officer to exercise the powers conferred” (Form 2; Part 2, Section 9, pp. 12, Mental Health Act, 2001), a member of Garda Siochana (Form 3) or a member of the public (Form 4).

b) Upon receipt of application, a registered medical practitioner must examine the individual within 24 hours. If the medical practitioner finds that the individual is suffering from a mental disorder that requires immediate medical attention through hospitalisation, a recommendation for an involuntary admission will be received by both the individual and the clinical director of the appropriate mental health service (Form 5). The recommendation has a validity of seven days within which the applicant is to coordinate the ‘removal’ of the individual to the mental health centre. The clinical director or a consultant psychiatrist may also enlist the help of the Garda Siochana or members of the mental health service in transporting the individual to the mental health centre if the individual is deemed likely to cause serious damage to himself or other persons.

c) Upon receipt of a recommendation of involuntary admission, a consultant psychiatrist must again examine the individual within 24 hours of detention. Following the examination, the consultant psychiatrist may either complete an involuntary admission order (Form 6) or refuse such order depending on whether he regards the individual to be suffering from a mental disorder that requires hospitalisation.

Under the Mental Health Act (2001), service users who were admitted to a hospital voluntarily may also be detained involuntarily. Completion of an involuntary admission order, for both new service users (Form 6) and service users who previously entered the approved mental health centre voluntarily (Form 13), is based on the following criteria:
• “because of the illness, disability or dementia, there is a serious likelihood of the person concerned causing immediate and serious harm to himself or herself or to other persons,

OR

• because of the severity of the illness, disability or dementia, the judgement of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a serious deterioration in his or her condition or would prevent the administration of appropriate treatment that could be given only by such admission,

AND

• the reception, detention and treatment of the person concerned in an approved centre would be likely to benefit or alleviate the condition of that person to a material extent.” (Part 1, Section 2, pp. 9, Mental Health Act, 2001).

When an admission order is placed, service users are placed under the care of the mental health service for a period of up to 21 days from admission (Mental Health Act, 2001). The consultant psychiatrist must inform the Mental Health Commission of the involuntary admission order who must, in turn, organise for a mental health tribunal to take place within 21 days of detention. The Mental Health Commission must ask an independent psychiatrist to re-examine the service user, re-evaluate their records and consult with their admitting physician. The service user must also be allocated a legal representative in the event that he or she does not already have one.

The purpose of the mental health tribunal is to re-examine all aspects pertaining to the admission. It will either affirm the involuntary admission order if the members of the tribunal perceive that there is evidence to sustain or revoke the order and ask for the service user to be discharged immediately if they regard the evidence for the involuntary admission order as an inaccurate portrayal of the service user’s mental health (Form 8). Members of the mental health tribunal may also decide to extend the service user’s detention in hospital for a period of fourteen days and revisit the service user’s case thereafter (Form 9). Following an involuntary admission, a renewal order may be in place for a period of three months which
can be subsequently extended for 6 months and a supplementary period of twelve months (Kelly, 2007).

### 1.1.2 Informed Consent

Additionally, the act provides detail on how to receive appropriate and informed consent to treatment. Informed consent must be obtained from service users for all treatment except for cases where the service user’s treating consultant psychiatrist regards the treatment as life-saving or necessary for the improvement of their mental health. This exception is applicable to service users who are impeded from giving informed consent due to a deterioration of their condition. Most importantly, informed consent must be given in the absence of any form of inducement or threat. Treatments such as restraint and seclusion fall into this category. The act states that individuals may only undergo seclusion or bodily restraint for the purpose of treatment or safety whereby there is an inherent risk of injury to either patient or other individuals. However, medication or treatment provided for three months uninterruptedly will be discontinued in the absence of informed consent from the service user or approval from two psychiatrists that cite that treatment is necessary for the recovery of the individual at a time when he or she is unable to give informed consent.

### 1.2 Psychiatric Admissions in Ireland

The most recent data available on Irish psychiatric admissions pertains to the Health Research Board’s Activities of Irish Psychiatric Units and Hospitals for the year 2013 and the Mental Health Commission’s 2013 Annual Report. A total of 18,457 psychiatric admissions took place in Ireland in 2013 (Health Research Board, 2014). Psychiatric admission in Ireland most frequently occurred in those aged between 35 and 44 years (20%, n = 3,768). A total of 12% (n = 2,182) of individuals were aged between 18-24 years, 19% (n = 3,567) were between 25-34 years and 18% (n = 3,403) were between 45-54 years. Those aged between 55-64 years (n = 2,734) and over 65 years old (n = 2,704) each represented 15% of the sample. In 2013, the rate of female service users (51%, n = 9,347) almost equalled that of male service users (49%, n = 9,110) overall (Health Research Board, 2014). Approximately half of those admitted to an Irish mental health centre were single (55%, n = 10,131). Twenty seven percent (n = 4,937) were married, 4% (n = 795) were widowed and a further 4% (n =
were divorced. Marital status was unspecified for 10% (n = 1,903) of those admitted (Health Research Board, 2014) (see Table 1).

In total, 15,250 admissions were linked to a primary diagnosis of a DSM-IV Axis I clinical disorder (Health Research Board, 2014). Depressive disorders were the most frequent primary diagnoses at admission (34%, n = 5,253). This was followed by schizophrenia, schizotypal and delusional disorders (24%, n = 3,691), mania (14%, n = 2,083) and neuroses (11%, n = 1,646). Alcohol use disorders accounted for approximately 10% of this population (n = 1,470) and other drug use disorders accounted for a further 6% (n = 890). The least frequent category of primary diagnosis at admission was linked to eating disorders (1%, n = 217) (see Table 1).

Table 1. Characteristics of involuntarily and voluntarily admitted service users in Ireland in 2013

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Involuntary</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1,182 (13)</td>
<td>7,928 (87)</td>
</tr>
<tr>
<td>Female</td>
<td>857 (9)</td>
<td>8,490 (91)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>250 (12)</td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>440 (21)</td>
<td></td>
</tr>
<tr>
<td>35-44</td>
<td>469 (22)</td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>346 (16)</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>280 (13)</td>
<td></td>
</tr>
<tr>
<td>65+</td>
<td>347 (16)</td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenic spectrum disorders</td>
<td>890 (53)</td>
<td>2,801 (21)</td>
</tr>
<tr>
<td>Mania</td>
<td>363 (22)</td>
<td>1,720 (13)</td>
</tr>
<tr>
<td>Depressive disorders</td>
<td>214 (13)</td>
<td>5,039 (37)</td>
</tr>
<tr>
<td>Neurosis</td>
<td>59 (4)</td>
<td>1,587 (12)</td>
</tr>
<tr>
<td>Alcohol disorders</td>
<td>51 (3)</td>
<td>1,419 (10)</td>
</tr>
<tr>
<td>Drug disorders</td>
<td>90 (5)</td>
<td>800 (6)</td>
</tr>
<tr>
<td>Eating disorders</td>
<td>6 (0.4)</td>
<td>211 (1)</td>
</tr>
</tbody>
</table>

In 2013, 2,132 involuntary admission orders took place in the Republic of Ireland (Mental Health Commission, 2014). A total of 57% (n = 900) of applications for an involuntary admission were submitted by a spouse or relative of the service user (Mental Health Commission, 2014). Approximately 1,600 of these involuntary admissions occurred under Form 6 and the remaining 541 involuntary admissions consisted of service users who were initially admitted voluntarily and subsequently detained (Form 13). The majority of those involuntarily admitted overall were male (54%, n = 1,155) (Mental Health Commission,
2014). Although voluntary admissions account for approximately 85% of all psychiatric admissions, the Mental Health Act (2011) does not provide a structure for such (Health Research Board, 2014; Kelly, 2007). Voluntary admissions were nearly gender-balanced (52% female, n = 8,490) (Health Research Board, 2014). The demographic characteristics of involuntarily and voluntarily admitted service users admitted to an Irish psychiatric hospital in 2013 are presented in Table 1. Unfortunately, neither the Mental Health Commission or the Health Research Board have released information pertaining to the marital statuses of those admitted involuntarily. Furthermore, no data are available relating to the average age of those voluntarily admitted or their marital status (Health Research Board, 2014; Mental Health Commission, 2014).

1.3 Coercion at Admission

Involuntary admission is linked to reports of coercion at admission. The term ‘coercion’ invokes a multiplicity of definitions ranging from imposing treatment against the person’s wishes (Olofsson, Gilje, Jacobsson, & Norberg, 1998) to any practice which involves a restraint on the individual’s autonomy without a clear benefit to the individual by the use of authority figures (Engelhardt, 1996; O’Brien & Golding, 2003). According to the Oxford English Dictionary (2015), to coerce is to “constrain or restrain (a voluntary or moral agent) by the application of superior force, or by authority resting on force”. Coercion is “both done to someone and experienced by someone”, or in other words, is both a subjective experience and an objective action (Hoge et al., 1993, p.282). Wertheimer (1993) suggests that coercion is contextually-dependent. It may be evident and administered prior to and at admission by both family members and mental health professionals and may be reinforced by staff during the period of hospitalisation in order to ensure treatment adherence.

Treatment pressures are divided into five distinct processes ascending in severity from persuasion, interpersonal leverage, inducements, threats and compulsion (Szmukler, 2008). Of the aforementioned practices, threats and compulsion are viewed as most coercive as they impinge on the service user’s autonomy by using force. At one end of the continuum, persuasion may refer to a gentle push or respectful attempt at reasoning with the service user. This may take the form of reminding the service user of past negative experiences where treatment may not have been adhered to. According to O’Brien and Golding (2003), both
persuasion and manipulation are to be regarded as coercive practices. For example, mental health practitioners who state that it is up to the individual to choose their form of treatment and subsequently abstain from giving them an appropriate level of information or provide false information so as to influence their judgement, are seen as conducting themselves coercively. Therefore, some forms of coercion are subtle and not always visible to the eye. Interpersonal leverage may occur when an intimate relationship exists between service user and clinician or caregiver. The service user may fear disappointing their treating clinician or caregiver and may agree to treatment in order to avoid feeling regarded as a ‘disappointment’ or otherwise. Offers or inducements pertaining to the admission or treatment may also occur (Canvin, Rugkasa, Sinclair, & Burns, 2013; Szmukler, 2008). For example, the service user may be offered or promised accommodation upon discharge in exchange for being admitted or adhering to treatment.

Conditional propositions such as threats are experienced by service users when, for example, hospital discharge is withheld unless the service user adheres to a treatment plan. Threats may occur at admission, for example, when the service user is told that if he or she does not admit themselves, they will experience the loss of a home, income or otherwise (Hiday, Swartz, Swanson, & Wagner, 1997). Service users may also report that they were threatened with involuntary admission had they not admitted themselves under a voluntary legal status. Involuntary admission to a hospital is regarded as the most serious form of coercive practice. It is also important to highlight that involuntary admission may also use physical force, whereby the individual may be forced into the mental health centre.

Coercive practices have, at times, been a part of mental health care. These practices were previously condoned by health professionals who believed they were acting in accordance with the medical principles of beneficence and non-maleficence. It was also encouraged by the supposition that mental illness may impair the individual’s judgement in acknowledging that they may need treatment (Priebe et al., 2009; Wertheimer, 1993). A debate has arisen in the psychiatric literature as to whether this practice should be justified and viewed as ‘in the best interest’ of the patient (Seale, Chaplin, Lelliott, & Quirk, 2006) or whether it acts as a portrayal of medical paternalism (Newton-Howes & Mullen, 2011; O'Brien & Golding, 2003). The use of coercion in psychiatry was traditionally justified in instances where patients were viewed as being incapable of making informed decisions and living autonomously (O'Brien & Golding, 2003). However, in recent times, mental health
professionals are “ethically and morally bound” to review and decrease coercive practices and impressions of coercion where possible (McKenna, Simpson, Coverdale, & Laidlaw, 2001, p. 573). This change arose as part of a human rights movement, whereby,

“every patient shall have the right to be treated in the least restrictive environment and with the least restrictive or intrusive treatment appropriate to the patient's health needs and the need to protect the physical safety of others” (United Nations, 1991).

We are not fully aware of how coercion affects service users’ course of treatment (Hoge et al., 1993; Hoyer, 2008; Iversen, 2002; Monahan et al., 1995). Arguments allowing the use of coercion have focused on the need to provide adequate care and protect others (Appelbaum, 1985). However, service users who experience coercion also report feeling dehumanised and neglected by the services (Newton-Howes & Mullen, 2011). Despite this lack of transparency, civil commitment to a mental health centre is authorised by mental health acts across the globe (Hoyer et al., 2002). Understanding the extent to which coercion occurs and the forms it takes may have important connotations for treatment outcome. For instance, fear of being involuntarily admitted may prevent service users from seeking help (Lucksted & Coursey, 1995).

1.4 Coercion and Perceived Coercion

A service user’s involuntary status and submission to coercive treatments during hospitalisation (i.e., use of restraint, forced medication, and seclusion) are normally documented in patient records (Kjellin & Westrin, 1998). Objective measurements of coercion at admission, however, have been fraught with methodological difficulties. It is important to distinguish actual coercion from perceived coercion when trying to establish whether coercion at admission occurred.

Traditionally, the service users’ legal status was used as the main indicator of coercion at admission (Hoyer et al., 2002; Iversen, Hoyer, & Sexton, 2007). This method, however, is obsolete and problematic for two reasons; it does not give us a clear indication as to whether service users perceived coercion at admission (Hoge et al., 1997; Monahan et al., 1995) nor do service users’ legal statuses always correlate with their perceptions of coercion (Bindman et al., 2005; Hiday et al., 1997; Iversen, 2002; Prebble, 2015). It is for this reason that later
research has shifted towards measuring subjective experiences, or perceptions, of coercion. Service users may, however, distort their experiences of admission, sometimes, due to their own thoughts regarding the morality or immorality of coercion (Monahan et al., 1995).

1.5 Service Users’ Perceptions of Coercion at Admission

Perceptions of coercion arise from experiencing a dearth of choice, freedom, influence or control with regards to one’s own admission to hospital (Gardner et al., 1993; Hiday et al., 1997). Key factors such as service users having a ‘voice’, sensing that expression of their opinion will be well received, ultimately understanding the reasons for their admission and seeing them as ‘fair’, as well as occurring in the absence of force or threats are important when reviewing the extent to which perceived coercion occurs. The power to assert one’s own choice freely and without coercion when admitted has also been conveyed as an important substitute for whether the individual was truly admitted involuntarily or voluntarily (Hoge et al., 1993; Hoge et al., 1997).

Understanding service users’ perceptions of their admission is imperative as these perceptions are linked to their treatment outcome. High levels of perceived coercion are linked to a poor therapeutic alliance between clinician and service user (Sheehan & Burns, 2011; Theodoridou, Schlatter, Ajdacic, Rossler, & Jager, 2012), dissatisfaction with mental health services (Katsakou et al., 2010), diminished treatment adherence as an out-patient (Kaltiala-Heino, Laippala, & Salokangas, 1997) and disengagement from mental health services (Lidz et al., 1998). It is, therefore, important for clinicians to identify such views and, where possible, revise whether their behaviours may be construed as coercive.

Perceptions of coercion were most frequently reported when service users (1) viewed their admission as forced, (2) felt excluded from the decision-making process prior to their admission, (3) felt that they were not given the time or consideration to express their stance and (4) felt that the reasoning behind their admission was unjustified or unfair (Lidz et al., 1998). In a qualitative study carried out by Katsakou et al., (2011), three themes corresponded to patients attributing feelings of coercion to their admission. These were self-observations or opinions regarding the inefficacy and inappropriateness of in-patient treatment as opposed to other forms of treatment, lack of involvement in one’s own
admission, not feeling cared for or respected by the treating team or staff as well as loss of sense of identity (Katsakou et al., 2011).

Involuntary admission and threats are highly correlated with service users’ perceptions of coercion (Lidz et al., 1998). Kjellin and Westrin (1999) found that approximately 40% of involuntarily admitted service users stated that they experienced coercion in the admission process. Sixty-five percent of these reported experiencing coercive practices during their stay in hospital even though the use of coercive measures was only recorded in 23% of involuntarily admitted service users’ charts. found that a third of involuntary patients believed they were mentally ill, approximately a quarter stated that it was their idea to come to hospital and over 40% expected to be admitted (Hoge et al., 1997). Furthermore, over 80% of involuntary patients stated that they were not asked (or offered) to admit themselves voluntarily. More than half of these specified that they would have accepted the offer had it been made. Seventy percent of involuntarily admitted service users stated that they were treated fairly and with respect and understood the motivation behind their admission. Fewer than 60% of involuntarily admitted individuals reported having a ‘voice’, a sense of validation and receiving information at admission. By comparison, 70% of voluntary service users reported experiencing all aspects of procedural justice (McKenna et al., 2001). In a follow-up study re-examining perceived coercion in involuntarily admitted patients one year after discharge, 40% of service users maintained that the reasoning for their involuntary admission was justified (Priebe et al., 2009). These findings also indicated that the service user’s judgment of the admission was constructed in the first week of hospital and tended to remain consistent throughout.

Similarly, some researchers have documented that a proportion of voluntarily admitted service users reported being the subject of coercive practices. In an observational study Gilboy (1971) described how legally voluntary patients were

“induced to voluntarily commit themselves with the threat of involuntary commitment as the principal means of persuasion, and with little concern for the adequacy of the information on which the individual’s decision is based or whether it is ‘voluntary’ at all” (Gilboy, 1971, p.430).
Monahan et al. (1995) highlighted that some of those admitted under a ‘voluntary’ status may also have effectively been ‘coerced’ to enter hospital by a legal guardian. Approximately 10% of their sample of voluntarily admitted service users reported perceptions of coercion. Monahan et al.’s (1995) findings are supported by various studies such as Kjellin and Westrin’s (1999) study, where 7% of those admitted voluntarily reported both being involuntarily admitted and experiencing coercion during their admission. Although voluntarily admitted, 28% of voluntary patients claimed to have been subjected to coercive measures during hospitalisation. This is remarkable as subjection to coercive measures is only regulated in cases of involuntarily admitted patients and all instances of coercive treatment must be documented. Most importantly and least highlighted, those admitted voluntarily who experienced coercion were the least protected by legislation as, similarly to the Irish Mental Health Act (2001), voluntary admission is not covered within Swedish mental health legislation (Hoge et al., 1997).

Almost half of Hoge et al.’s (1997) sample of voluntarily admitted service users did not believe they were mentally unwell and did not choose to be admitted. Moreover, less than half of the service users expected to be admitted when going to the hospital. Forty-four percent of voluntary patients stated that it was not their idea to enter hospital and slightly fewer (39%) believed that they would have been admitted involuntarily had they not signed themselves in. Just over 10% of voluntarily admitted individuals stated that their impending admission was unequivocally divulged to them and that it would occur against their will should they choose not to admit themselves. A quarter felt that there were other treatment alternatives other than hospitalisation and 3% reported being deceived into admitting themselves voluntarily. In a different study conducted by the same principal author, (Hoge et al., 1993), a fraction of voluntarily admitted service users were not aware that a member of staff from their mental health centre planned to complete an involuntary order had the individual not agreed to enter the hospital voluntarily.

In those admitted involuntarily, between 41-51% reported low levels of coercion (Iversen et al., 2007; Iversen, 2002). Seven to thirty-three percent of voluntarily admitted individuals reported high levels of perceived coercion (Kjellin & Westrin, 1999; Monahan et al., 1995; Katsakou et al., 2011) Additionally, those who were further detained after an initial voluntary admission tended to report experiences of coercion (Poulson, 1999). The latter experience, however, was distinguished from involuntary admission and viewed as less coercive. In terms
of treatment pressures, a third of involuntary service users narrated that they experienced persuasion. A smaller portion revealed that they experienced inducements and threats. Nearly half of all involuntarily admitted service users stated that they were forced into admission. In voluntarily admitted service users, experiences of persuasion occurred in nearly half the sample. Inducements, threats and force occurred to a lesser degree. It is therefore clear that, when measuring perceived coercion in service users, it is important to bear in mind that these perceptions are not exclusively experienced by those who are involuntarily admitted. Such measurements should also aim to include those who were voluntarily admitted where possible.

Due to the plausible power imbalance between admitting clinician and patient, it is possible that the patient may view as ‘threat’ what may have genuinely been designed as persuasion by the clinician (Monahan et al., 1995). Additionally, some patients report feeling coerced without any evidence of coercive treatment or interactions being found to support their claim (Hoge et al., 1997). Hoge et al. (1993) indicated that service users report fewer experiences of negative pressures in comparison to clinicians and family members. Service users may be more likely to comprehend and pardon coercive actions carried out by those around them when evaluating the relationship between them and the executor of the action rather than the action alone. Furthermore, perceiving an action as coercive is dependent on the individual’s sensitivity and level of awareness of the circumstances leading up to and during their admission (Hoge et al., 1993). The use of coercion may be a final attempt at engaging the patient in treatment where less serious approaches have failed (Lidz et al., 1998).

1.6 Coercion in Irish Psychiatric Admissions

In Ireland, two important quantitative studies on perceptions of coercion in adult psychiatry have emerged. One was designed to examine service users’ perceptions regarding their involuntarily admission to one Dublin hospital (O'Donoghue et al., 2011). In this study, the majority of service users felt that their admission was necessary and beneficial to them. Insight into illness and duration of hospitalisation were accurate predictors of perceived necessity of admission in involuntarily admitted service users. The most recent quantitative Irish study found that service users’ perceptions of coercion did not differ according to whether the involuntarily or voluntarily admitted individual was interviewed by another service user or by a clinician (O'Donoghue et al., 2013). O'Donoghue et al. (2013) also found
that over half of involuntarily admitted individuals and nearly all of those admitted voluntarily perceived their admission as necessary.

1.7 Caregivers’ perceptions of coercion at admission

At present, we have a dearth of data on caregivers’ perceptions of coercion during their relative’s admission and hospitalisation. Such appraisals or perceptions may be important as they may affect the service user’s prognosis (Kuipers, 2010; Sczuufca & Kuipers, 1996), adherence to treatment (Sher, McGinn, Sirey, & Meyers, 2005) and, in turn, the possibility of subsequent re-admissions (Haywood et al., 1995). Caregivers’ perceptions of the admission may naturally differ to service users’ perceptions as they represent second hand experiences of the admission. However, these accounts may provide a clearer description of the admission if the service user suffered from an acute psychotic illness that resulted in a diminished level of insight at the time of the admission (McEvoy et al., 1989).

Three studies have shed some light on caregivers’ perspectives of the service user’s admission (Hoge et al., 1993; Hoge et al., 1998; Kjellin & Westrin, 1999). The most crucial of these, that directly compared caregivers’ perceptions of coercion, pressures and procedural justice to those of the service users’ was conducted by Hoge and colleagues in 1998. In Hoge et al.’s (1998) study, caregivers’ were found to report more positive experiences of the admission than the service user and perceived lower levels of perceived coercion and pressures and higher levels of procedural justice than service users. Another study, by Kjellin and Westrin (1999), examining perceived coercion in caregivers and service users conveyed that coercion was identified by caregivers during their relative’s care in hospital and that the use of coercive measures was also apparent in a small number of service users who were admitted voluntarily (Kjellin et al., 2004). Finally, in an earlier study by Hoge and colleagues (1993) that loosely examined perceptions of admission in caregivers, service users and clinical staff, service users perceived the admission as more pressured and perceived more alternatives to hospitalisation than staff or relatives. Caregivers, on the other hand, perceived the admission as necessary as hospitalisation occurred due to their inability to cope any further. Although, they indicated that admission was their last resort to gain medical help, they also frequently indicated that their relative was pressurised at admission.
In conclusion, this chapter described how service users can be legally admitted to psychiatric hospital in Ireland and the most recent rates of both involuntary and voluntary admission. We are now more familiar with the types of coercion that may occur at admission and how service users may perceive their admission and, in particular, whether they perceive their admission as coerced, pressured and procedurally just. Unfortunately, we are lacking such familiarity with the caregiver’s perspective of their relative’s admission in Ireland and worldwide. The present study will aim to bridge this gap by obtaining the caregiver’s perspective and, where possible, comparing it to that of the service user’s. Before embarking on this analysis, the next chapter will, firstly, illustrate, by means of a literature review, the experiences of being a mental health caregiver.
Chapter Two

Literature Review

The previous chapter in this thesis described the Irish Mental Health Act 2001 and listed the most recent prevalence rates for involuntary and voluntary psychiatric admission in Ireland. It outlined the literature and detrimental effects of service users’ perceptions of coercion and described the limited literature available on caregivers’ perceptions of coercion worldwide. Although the caregivers’ perspective of the admission is central to this thesis, it is necessary to understand whether there are contextual and psychological factors related to caregiving that may affect this perspective. This next chapter will explain what is known about caregivers’ experiences of caregiving in the form of a literature review. A stress-coping paradigm will be used to understand how caregivers perceive their role and the experience of caregiving. The literature included in this chapter is the result of extensive literature searches on the following search engines: Pubmed, Web of Science, Scopus and Google Scholar. An example of a search term that used was (“mental” OR “psych*”) AND (“caregiver”), or (“mental” OR “psych*”) AND (“expressed emotion”). As some databases found large numbers of caregiving publications pertaining to neurocognitive, ageing or physical illnesses, there were excluded using the ‘NOT’ function when looking at specific constructs.

2.1 Caregiving

The term ‘caregiver’ refers to an unpaid individual who cares for and supports a person who has an illness that, at times, impedes them from coping without support (Carers Trust, 2015). In Ireland, approximately 183,000 individuals act as caregivers (Central Statistics Office, 2011). Over a third of these provide care to an individual with a mental disorder (O'Brien, 2009). Caregivers can act as ‘invisible’ pillars of support to service users and services (Arno, Levine, & Memmott, 1999; Ohaeri, 2003). Additionally to providing practical and emotional care to the service user, they may encourage adherence to treatment (Pinfeld, 2007). Furthermore, they may provide indispensable information to services on the circumstances
that led to the admission (Wallace, Robertson, Millar, & Frisch, 1999) as well as details on previous episodes of illness (Kjellin & Ostman, 2005).

The importance of the role of carers was acknowledged in Irish policy report ‘A Vision for Change’ (Department of Health and Children, 2006). Caregivers are increasingly involved in the care of mental health service users due to a shift from institutionalisation to community based treatment (Chang & Horrocks, 2006; Thornicroft & Tansella, 2005). This form of treatment may encourage positive developments whereby those who experience mental health difficulties are looked after in their family home and integrated within society (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004). However, there are indications that this increase in responsibility creates significant challenges for carers of individuals with a serious mental illness.

Caregiving is perceived by many caregivers as a burdensome experience due to chronic exposure to stressors that can cause both physical and psychological strain (Schulz & Sherwood, 2008). In turn, constant exposure to stress may lead to difficulties in other areas within the caregiver’s life such as social isolation and work disruptions. Caregivers are more likely to be afflicted by both anxiety and affective disorders than non-caregivers (Cochrane, Goering, & Rogers, 1997). Although the above difficulties are common to all types of caregivers, it is important to note that experiences of caregiving may differ according to the illness of the relative cared for. One key study that compared the experiences of dementia caregivers to caregivers of individuals with a serious mental illness found some key experiential differences between the two (Biegel & Schulz, 1999). Individuals with dementia were typically older adults whose illness led to anticipated cognitive and physical declines in functioning. Caregiving, in this group, is normally expected, focused on ‘hands on’ care, and delivered by grown up children or spouses of the individual. These caregivers tend to have higher instances of mortality (Schulz & Sherwood, 2008).

Individuals with a serious mental illness, on the other hand, are typically young and transitioning between the key developmental stages of adolescence and adulthood when first struck by an illness that causes cognitive impairment (Biegel & Schulz, 1999). As a result, caregiving in this group can be wholly unexpected, unpredictable due to the cyclical nature of illness, and unwanted by a young adult who desires greater independence from family. Caregivers of these individuals are tasked with invigilating their relative’s behaviour and experience greater difficulties in accessing appropriate support. This, in part, is due to
experiencing stigma from their surrounding community and, in part, due to the unavailability of family-oriented, rather than medical, mental health services (Biegel & Schulz, 1999).

Understanding the caregiver’s experience of caring through research, nevertheless, is fraught with methodological difficulties. Many studies have heterogenous samples, heterogenous service user diagnostic populations or instrumental and theoretical inconsistencies (Biegel & Schulz, 1999). In addition to these disparities, we are missing mixed-methods and longitudinal data to consolidate our understanding of caregiving (Baronet, 1999; Biegel & Schulz, 1999). Nevertheless, a number of theoretical models have been proposed to better understand the experiences of caregiving. The most prominent of these, Lazarus and Folkman’s (1984) theoretical stress and coping framework, has been adopted by multiple researchers to describe the effect of caregiving on the caregiver’s life and wellbeing (Biegel & Schulz, 1999; Mackay & Pakenham, 2012; Stansfeld et al., 2014; Szmukler, Herrman, Colusa, Benson, & Bloch, 1996).

2.2 Using a Stress-Coping Theoretical Framework

According to this model, individuals experience a primary stressor such as an episode of illness or problematic behaviour that poses a limitation or demand (Biegel & Schulz, 1999). Upon experiencing the stressor, individuals appraise their ability to cope with it and adopt a coping strategy (Mackay & Pakenham, 2012). Individuals’ perceptions regarding their ability to cope and the changeable nature of the problem are then re-appraised following their first attempt at coping (Folkman & Lazarus, 1988; Provencher, Fournier, Perreault, & Vezina, 2000). If the stressor continues to threaten to exceed their coping reserves, they may experience negative affect in the form of anxious or depressive symptoms (Biegel & Schulz, 1999). For example, mental health caregivers who experience their relative’s first episode of psychosis may appraise themselves as unable to cope and may seek outside help as a coping strategy. If unable to access such help whilst their relative is acutely unwell, their appraisal of their own ability to cope may worsen and may lead to symptoms of mental health difficulties.
Part I: Contextual variables

Despite the face validity of the model in the context of caregivers, applying this model to a mental health caregiving scenario may be more complex than originally perceived. Firstly, the caregiver’s context and both the caregiver’s and service user’s characteristics and type of relationship prior to illness may influence the former’s ability to adjust to potential stressors (Kuipers, Onwumere, & Bebbington, 2010; Stansfeld et al., 2014). Examples of contextual factors likely to influence caregiving may be demographic in nature, or may pertain to the service user or to caregiving (Mackay & Pakenham, 2012; Stansfeld et al., 2014). With regards to demographic factors, in the UK, two large-scale studies identified caregivers as predominantly female, 50-64 years old, married, unemployed or not recently working and in receipt of a low income (Smith et al., 2014; Stansfeld et al., 2014). Examples of contextual factors linked to mental health service users or caregiving may relate to the type of illness suffered by the service user, the type and quality of relationship between caregiver and service user, the age of the service user at first illness, living arrangements, perceptions of societal stigma towards mental illness and the caregiver’s willingness to act as a caregiver (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Biegel & Schulz, 1999). The most research targeted contextual factor in caregiving concerns caregiver burden. For example, caregivers who care for service users who have an illness that may require more personal care on top of other caregiving tasks, for instance, helping with bathing, dressing and toileting may find caregiving most challenging. Ageing caregivers, in particular, may find involvement in such tasks physically restrictive. Living with the service user may lead to greater instances of sleep disturbance and tends to be linked with higher instances of caregiving-related distress. Furthermore, providing care unwillingly may cause significant disturbance to caregivers who feel they do not have a choice.

Caregiver burden refers to the negative outcomes of caregiving (Schulze & Rossler, 2005). The available literature on caregiver burden has failed to clarify an exact definition of burden. As such, definitions for this term range from “the negative consequences to families related to their caregiving roles” (Rose, Mallinson, & Walton-Moss, 2002, p. 518) to “adverse events when caregivers assume an unpaid and unanticipated responsibility for a care recipient” (Schulze & Rossler, 2005, p. 684). It has been often been divided into two categories: objective and subjective burden based on the source and type of difficulties. Objective burden is linked to social and occupational difficulties caused by the relative’s illness such as routine and work disruptions. Subjective burden, conversely, refers to emotional difficulties, such as
psychological distress, that arise in those that care for or frequent the service user (Hoenig & Hamilton, 1966). The most frequently reported forms of objective burden were disruptions in personal or household routines and family conflict (Reinhard, 1994). Worry for the future and managing feelings of loss were the most frequently reported subjective impediments (Reinhard, 1994). Such feeling of loss may refer to feeling grief for the service user’s circumstances following the illness and for, at times, a past relationship or future hopes the caregiver may have had for the service user’s and their own life that they now feel are quashed.

Mental health professionals’ understanding of caregiver burden is critical to helping both the service user and caregiver. In a small number of studies the level of burden experienced by caregivers has been shown to significantly predict the service user’s treatment outcome and adherence to treatment in individuals with schizophrenia (Lasebikan & Ayinde, 2013; Perlick et al., 2004). However, there are difficulties determining the best method of measuring adherence to treatment and it is unclear whether this finding is replicable in other diagnostic populations and, on the whole, generalizable. Nevertheless, caregivers who experienced high levels of burden revealed an increased instance of physical and mental health problems and health risk behaviour (Perlick et al., 2007).

A number of predictors of caregiver burden have emerged in the literature. Higher caregiver burden is linked to a higher level of disability (Magliano et al., 2002; Ohaeri, 2003), a lower level of functioning (Magliano et al., 2002; Tang, Leung, & Lam, 2008), and a higher frequency or gravity of disruptive behaviour in the person being cared for (Biegel, Milligan, Putnam, & Song, 1994; Perlick, Stastny, Mattis, & Teresi, 1992). Higher levels of caregiver burden tend to be more prevalent in mothers, in caregivers who have attained a lower level of education, in those caring for younger service users and in those whose relatives have experienced multiple hospitalisations within a period of three years (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). Additionally, burden was found to be greater in carers who lived in areas which had lower or limited possibility for inpatient care (Becker et al., 2002). Burden appears to be indicative of a low level of perceived social support from family and mental health professionals (Biegel et al., 1994; Moller-Leimkuhler & Wiesheu, 2012; Song, Biegel, & Milligan, 1997).

Caregiver burden has been noted in caregivers of service users with a psychotic spectrum disorder, affective disorder, anxiety disorder and obsessive compulsive disorder (Moller-
Leimkuhler & Wiesheu, 2012; Ohaeri, 2003; Ostman, Wallsten, & Kjellin, 2005; Schulze & Rossler, 2005; Tang et al., 2008; Treasure et al., 2001). However, no one diagnosis was more conclusively associated with caregiver burden than another. Nevertheless, it may be important to note that the presence of negative symptoms in service users with schizophrenia is associated with both objective and subjective caregiver burden (Fadden, Bebbington, & Kuipers, 1987; Provencher & Mueser, 1997; Reinares et al., 2006; Tucker, Barker, & Gregoire, 1998; Webb et al., 1998). Subjective burden, however, was also linked to the presence of positive symptoms (Provencher & Mueser, 1997; Webb et al., 1998).

Research has acknowledged the parental, spousal, fraternal and filial burden of caregiving (Greenberg, Kim, & Greenley, 1997; Horwitz & Reinhard, 1995; Jungbauer et al., 2004; Ostman, Hansson, & Andersson, 2000; Pickett, Cook, Cohler, & Solomon, 1997; Wittmund, Wilms, Mory, & Angermeyer, 2002). Family studies on burden have tended to focus on the effects of caregiving on parents (Stalberg, Ekerwald, & Hultman, 2004). In one key study by Jungbauer et al. (2004), parents and spouses both experienced similar difficulties related to living with an individual with chronic and acute mental illness; both perceived differences in the service user’s personality during acute illness and feared the possibility of future relapse. Whilst spouses expressed marital difficulties and performed a re-evaluation of their shared lives, it was ultimately parents who assumed a lifelong sense of responsibility and dependency (Jungbauer et al., 2004). This sense of responsibility was particularly burdening to ageing parental caregivers who worried about the service user’s future ability to look after him or herself (Lefley, 1987). According to Ostman et al. (2005), siblings experienced the least amount of burden. They expressed love towards their sibling, sorrow and anger due to their sibling’s illness and envy of their sibling’s received attention (Stalberg et al., 2004). They also feared the possibility of being genetically predisposed to the same mental illness (Stalberg et al., 2004). Grown-up children who acted as caregivers to their parent revealed a high frequency of mental health difficulties and perceived their relationship as negatively affected by the illness (Ostman et al., 2005). Finally, regardless of the shared relationship between caregiver and service user, there is disagreement between studies as to whether living with the caregiver or higher contact frequency influences caregiver burden (Addington, Coldham, Jones, Ko, & Addington, 2003; Becker et al., 2002; Thornicroft et al., 2004).

Caregiving is facilitated by an underlying affection for the service user (Cormac & Tihanyi, 2006). Caregivers’ aspirations to be involved in the service user’s life are often underpinned by a desire to see their relative achieve a state of normality (Rose et al., 2002). The construct
of burden has been criticised for overly focusing on the negative aspects of caring to the detriment of the positive (Awad & Voruganti, 2008; Szmukler, Burgess, et al., 1996). According to Cormac and Tihanyi (2006), caregivers experience satisfaction and wellbeing from helping the care recipient, which is often unaccounted for in the psychiatric literature. Furthermore, caregivers reported improvements in their caregiver-care recipient relationship due to a new level of understanding of mental illness (Szmukler et al., 1996). Experiencing acute mental illness within the nuclear family led to a perception of increased resilience related to future reoccurrences of illness (Szmukler et al., 1996).

**Part II: Appraisal**

Caregivers’ appraisals of their relative’s illness also shape their experiences of caregiving (Kuipers et al., 2010). In line with Lazarus and Folkman’s model, appraisals within a mental health caregiving context, are characterized by thoughts regarding the service user’s illness targeted at reducing or tolerating the effects of the illness (Folkman & Lazarus, 1980). In the context of caregiving, primary appraisals may occur following the appearance of illness and, secondarily, following initial attempts at coping. Such appraisals can be divided into appraisals regarding threat of harm, loss or challenge (primary) and controllability (secondary) (Mackay & Pakenham, 2012; McCrae, 1984). The interactions between caregivers’ personal characteristics and environmental cues ultimately shape a caregiver’s appraisal (Barrowclough & Parle, 1997). The extent to which an individual is distressed by a stressor depends on their a coping resources and appraisals (Folkman & Lazarus, 1980). Coping resources refer to characteristics within an individual’s life that strengthen their ability to adjust to stressors (Mackay & Pakenham, 2012). The most noted coping resource within the mental health caregiving literature pertains to availability of social support. This may include support received from the service user (Baronet, 2003) or from individuals outside the caregiver-care recipient relationship (Webb et al., 1998). Caregivers who are enveloped into supportive social networks tend to convey lower instances of burden (Magliano et al., 2003). Such support may help caregivers by providing them with assistance and helping them achieve a sense of mastery and self-esteem that shapes their appraisal and coping processes (Doornbos, 1997). Appraisals regarding the illness shape the affective and behavioural reactions of caregivers. Understanding the caregiver’s appraisal of the illness and the coping resources available to them is important as it has the potential to affect both the
Caregiver’s outcome and the service user’s recovery (Bebbington & Kuipers, 1994; Birchwood, Mason, MacMillan, & Healy, 1993; Scazufca & Kuipers, 1996). Negative appraisals are linked to a higher degree of psychological distress (Haigh, 2003; Treasure et al., 2001). Positive appraisals, in turn, are linked to lower instances of distress (Jansen et al., 2015). When appraisals or perceptions regarding the service user’s illness differ between caregivers and service users, caregivers’ affect and self-esteem may lessen (Kuipers et al., 2010; Kuipers et al., 2007; Leventhal, 1992).

Appraisals may be dependent on the implicit attributions the caregiver holds. Caregiver attributions of the service user’s behaviour and illness may be an indication of how the caregiver perceives their relationship with the service user. In line with this argument, relatives who feel that the service user is responsible for their symptoms and behaviour may be more likely to feel and act like a victim in the relationship (Weigel, Langdon, Collins, & O’Brien, 2006). Contrastingly, caregivers who feel they are partly responsible for the service user’s illness may become overinvolved and may try to compensate by controlling or overindulging behaviours (Bentsen et al., 1998). Caregivers who attributed the service user’s illness to their personality traits revealed lower positive appraisals (Whitney, Haigh, Weinman, & Treasure, 2007).

Appraisals appear as a precursor to the construct of expressed emotion in the literature (Bentsen et al., 1998). Expressed emotion (EE) refers to the presence of emotional overinvolvement (EOI), criticism and hostility in the speech of family members towards their unwell relative (Kuipers, 1979; Vaughn & Leff, 1976). It gauges the type of verbal interactions that occur within a family. Brown and colleagues proposed the construct of EE as a measure of the caregiver’s perception of their relative with schizophrenia (Brown & Rutter, 1966). Early measurement, through the Camberwell Family Interview (CFI), recorded both objective circumstantial evaluations of the family environment and subjective perceptions of the service user as verbally described by the caregiver (Brown, Birley, & Wing, 1972). The CFI originally included measures of emotional overinvolvement, criticism, hostility, dissatisfaction and warmth (Brown et al., 1972). However, today, following experimental developments by Brown and colleagues, it solely and universally assesses the extent to which caregivers’ express critical, emotionally overinvolved and hostile remarks towards a service user as these three elements were found to most predict relapse (Kuipers, 1992). Criticism refers to the expression of disapproval of a service user or their behaviour, whereas, hostility is underpinned by a general rejection of the person. Emotional over-involvement
(EOI) is composed of three sub-constructs: excessive intrusion by the relative into the service user’s life, unwarranted ‘self-sacrificing behaviour’ and disproportionate worry for the service user’s wellbeing (Simmons, Chambless, & Gordon, 2008, p.408). Caregivers were described as having a high level of expressed emotion when they articulated more than a preset threshold of hostile, critical or emotionally overinvolved remarks (Butzlaff & Hooley, 1998; Hooley, 1986). However, researchers have noted difference in attributions between high expressed emotion families and low expressed emotion families. According to Greenley (1986) and Hooley (1985) high expressed emotion families endeavour to change or ‘fix’ the service user’s behaviour in an effort to gain a sense of personal control. However, they also differed on the types of attributions made. Whilst Greenley’s ideas centred on caregivers discerning perceptions of whether their relative was suffering from a mental illness or not, Hooley’s theory focused on caregiver control and choice. Following Hooley’s theory, behaviours that were unwanted and considered as fixable were met with criticism. Conversely, low expressed emotion families showed understanding for their relative’s difficult experiences and associate these to the service user’s illness (Leff & Vaughn, 1980, 1985).

Criticism and hostility may be indicative of a poorer relationship prior to the onset of illness (Kuipers et al., 2010). Service users, perceiving their relatives as unhelpful, may refrain from disclosing their symptoms until their severity necessitates a mental health admission (Kuipers et al., 2010). In turn, criticism and hostility may lead to higher levels of anxiety and depression in caregivers (Bentsen et al., 1998). Both have also been linked to higher levels of functioning and frequent (3 or more) hospitalisations. The caregiver’s criticism and hostility, however, may due to a perception of their relative’s superior level of cognitive functioning ((Bentsen et al., 1998; Boye et al., 1999).

Emotional overinvolvement, (EOI) on the other hand, coincides with feelings of guilt, loss and protectiveness (Leff & Vaughan, 1985; Patterson, Birchwood, & Cochrane, 2005; Peterson & Docherty, 2004). It is a buffering response aimed at protecting the service user (Kuipers et al., 2010). Caregivers who are emotionally overinvolved tend to attribute negative behaviours to the service user’s illness and the illness itself as beyond the service user’s control (Leff & Vaughan, 1985; Weigel et al., 2006). High levels of emotional overinvolvement are predominant in single mothers, in those living in a single parent household, in those who have greater contact frequency with the service user and in caregivers with anxiety or depressive symptoms (Bentsen et al., 1996). Unlike criticism and
hostility, emotional overinvolvement does not appear to be associated with the service user’s number of hospitalisations or level of functioning (Bentsen et al., 1998). Rather, it is affiliated with distress (Jansen et al., 2015). Service users from emotionally overinvolved families tended to have more enduring symptoms upon discharge compared to those whose families were critical or hostile (Miklowitz, Goldstein, & Falloon, 1983).

High expressed emotion may be damaging to both caregivers and service users. In caregivers, it can reveal ongoing mental and physical difficulties (Breitborde, Lopez, & Kopelowicz, 2010; Kuipers et al., 2010). In service users, it has been linked to patient relapse (Bebbington & Kuipers, 1994; Vaughn & Leff, 1976). Service users returning to families with high expressed emotion tend to relapse twice as often as those returning to low expressed emotion homes (Bebbington & Kuipers, 1994). Its ability to predict relapse extends to service users with mood disorders such as depression (Butzlaff & Hooley, 1998; Hooley, Orley, & Teasdale, 1986; Simmons et al., 2008) and bipolar disorder (Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988; Weigel et al., 2006), anxiety disorders (Simmons et al., 2008) and schizophrenia (Barrelet, Ferrero, Szigethy, Giddey, & Pellizzer, 1990; Butzlaff & Hooley, 1998; Cechnicki, Bielanska, Hanuszkiewicz, & Daren, 2013; Parker & Hadzi-Pavlovic, 1990; Sczufca, Kuipers, & Menezes, 2001). However, a recent and updated meta-analysis on studies examining expressed emotion and relapse may be warranted. Expressed emotion in caregivers of service users with an eating disorder was linked to treatment dropout (Szmukler, Eisler, Russell, & Dare, 1985). In those whose relative had psychosis, high expressed emotion overall was not linked to the service user’s duration of illness, symptom severity, diagnosis or age at onset of illness (Raune, Kuipers, & Bebbington, 2004). Furthermore, there is conflicting evidence on whether the caregiver’s perception of the service user’s level of functioning is related to high levels of expressed emotion (Raune et al., 2004; Sczufca & Kuipers, 1996; Smith, Birchwood, Cochrane, & George, 1993).

Studies examining the causal nature of frequency of attributions between high and low expressed emotion caregivers have reported mixed results (Grice et al., 2009; Hooley et al., 1986). Nevertheless, relatives who displayed high levels of hostility and criticism towards the service user tended to hold the service user responsible for their illness (Weigel et al., 2006) and view the service user as in control of their behaviour (Grice et al., 2009). These relatives perceive that negative symptoms are carried out intentionally by the service user (Sczufca et al., 2001; Simmons et al., 2008). These behaviours are misconstrued as a symptom of the service user’s character rather than their illness (Weisman, Nuechterlein, Goldstein, &
Snyder, 1998). Positive symptoms, on the other hand, are often portrayed as being outside the relative’s locus of control (Brewin, MacCarthy, Duda, & Vaughn, 1991).

The emergence of expressed emotion aided the growth of family intervention programmes (Hashemi & Cochrane, 1999) that included psycho-education, relapse prevention through expressed emotion reduction, stress management and problem-solving (Dennis & Leach, 2007). Such family interventions were found to reduce the rate of relapse in service users who belonged to families with high expressed emotion (Pharoah, Mari, & Streiner, 2010; Pitschel-Walz, 2001). However, levels of expressed emotion tend to change for approximately a quarter to a third of families without intervention (Patterson et al., 2005; Scazufca & Kuipers, 1998). Hooley et al. (1986) suggest that service users may become habituated to expressed emotion and that its impact may be dependent on the type of relationship between caregiver and care recipient. For example, a pattern of expressed emotion present since a younger age and received from a parental figure may elicit a different degree of tolerance to that of a spouse who may terminate such relationship. Yet these are suppositions. Further data is needed on whether expressed emotion differs according to the type of relationship shared between the caregiver and service user.

Part III: Coping

Coping is a behaviour that individuals adopt in response to a problematic situation (McCrae, 1984; Pearlin & Schooler, 1978). It refers to an individual’s “cognitive and behavioural efforts to master, reduce, or tolerate” a stressor (Folkman, 1984, p.843; Provencher et al., 2000). When a problem arises, individuals draw on various coping strategies that determine their coping outcome (Folkman & Lazarus, 1980). The appraisal formed by the caregiver and the coping resources available to them will determine the coping mechanism they adopt (Kuipers et al., 2010). Understanding whether and why caregivers adopt unhelpful coping mechanisms when faced with the service user’s illness is important in order to prevent harmful strategies from becoming adopted indefinitely (Scazufca & Kuipers, 1999). We, however, do not yet know whether caregivers’ coping style may have any direct effect on the service user’s outcome (Magliano et al., 1999).

Unhelpful or dysfunctional coping mechanisms are linked to negative appraisals of caregiving, higher levels of psychological distress and anxious and depressive symptoms
(Jansen et al., 2015; Onwumere et al., 2011; Scazufca & Kuipers, 1999). It is, however, unclear whether distress influences coping or vice versa. Folkman and Lazarus (1985) posited that this relationship may be bidirectional whereby both factors influence each other. Caregivers who present with a history of anxiety and depression may appraise their relative’s illness as unmanageable and their ability to cope as unfruitful. In turn, they may engage in unhelpful coping strategies that perpetuate their distress (Barrowclough & Parle, 1997). Poorer coping is, in fact, found in caregivers who feel more burdened, especially when coping resources and social support are unavailable to the caregiver (Magliano, Fadden, Economou, et al., 1998; Scazufca & Kuipers, 1999) and who display greater levels of expressed emotion (Birchwood & Cochrane, 1990; Scazufca & Kuipers, 1999). In turn, those who feel less able to cope with the service user’s illness are more likely to feel burdened and tend to adopt more avoidant forms of coping (Roick, Heider, Toumi, & Angermeyer, 2006; Scazufca & Kuipers, 1999; Smith et al., 1993). This is particularly noticeable in those who are emotionally overinvolved (Scazufca & Kuipers, 1999).

Caregivers employ differing coping mechanisms to cope with their relative’s illness and difficulties related to it (Birchwood & Cochrane, 1990). Within the mental health literature, these can be broadly divided into two categories: emotion-focused coping strategies and problem-focused coping strategies (Folkman & Lazarus, 1985). Emotion-focused coping refers to an individual’s coping methods aimed at adjusting their level of distress. Problem-focused coping refers to the actions individuals undertake to ameliorate the problematic situation they are faced with. Both forms of coping may be useful depending on the individual’s problem. For example, emotion-focused coping may help the individual recalibrate their emotional response to a problem that is viewed as insurmountable (Folkman, 1991). Contrastingly, those who view a problem as fixable or potentially changeable may employ problem-focused coping strategies in an attempt to resolve such a problem. However, both forms of coping may be maladaptive when used in the wrong context. For example, emotion-focused coping such as avoidant behaviour may be detrimental to caregivers when faced with a difficulty requiring problem-solving (Dyck, Short, & Vitaliano, 1999).

Within the literature, a vast number of coping styles appear. Such coping styles can differ in name between studies. However, these tend to be grouped into two main types of coping: emotion-focused and problem-focused coping. In a recent study by Cotton et al. (2013), caregivers were found to experience five types of coping styles. The first and most predominant of these, cognitive escape, referred to cognitive states such as wishfulness,
hopelessness and cognitive avoidance. The second of these, tension reduction, focused on reducing distress or tension by adopting avoidant behaviour such as personal avoidance and substance use. Thirdly, distancing, was characterised by the use of distraction or situational avoidance. Unlike the previous three avoidant coping styles, the remaining two coping styles referred to positive behaviours. Optimistic coping was exemplified by positive thinking and problem-targeted action. Finally, connection, referred to caregivers’ attempts to seek both emotional and instrumental support from peers, family or professionals in trying to help the caregiver.

Avoidant coping strategies such as cognitive escape, tension reduction and distancing were linked to higher levels of psychological distress and caregiver burden (Cotton et al., 2013; Goossens, Van Wijngaarden, Knoppert-van Der Klein, & Van Achterberg, 2008; Hinrichsen & Lieberman, 1999; Onwumere et al., 2011). The first of these, cognitive escape, may represent caregivers’ attempts to avoid or decrease their negative emotional response to the service user (Folkman & Lazarus, 1985). The latter two may represent avoidant behaviours aimed at reducing distress. Furthermore, using self-blame as a coping strategy was linked to higher instances of distress (Fortune, Smith, & Garvey, 2005). In turn, lower levels of psychological distress were linked to seeking coping styles named emotional support, using active coping, acceptance, positive reframing and religion (Fortune et al., 2005).

Higher levels of burden, overall, can be linked to emotion-focused coping and coping mechanisms such as coercion, avoidance and resignation (Hanzawa et al., 2010; Magliano et al., 2000). Three of the four dimensions of burden, namely urging, tension and worrying, were linked to distraction coping and inability to cope due to feeling overwhelmed (Goossens et al., 2008). Additionally, patterns of tension reduction and distancing were associated with burden in caregivers observing negative symptoms in service users with psychosis. These forms of coping may be used by caregivers who find these symptoms difficult to cope with (Cotton et al., 2013).

Avoidant coping strategies may, however, also be valuable to caregivers. These may allow caregivers to distract themselves from thinking of the service user’s illness and, in turn, facilitate positive thoughts towards the service user (Cotton et al., 2013). They may be particularly helpful to caregivers who feel burdened by negative symptoms (Fadden et al., 1987) or in circumstances where the presenting issue may improve without attempts at problem-solving (Kuipers et al., 2010). However, the use of avoidant coping strategies is also
linked to higher levels of expressed emotion (Scazufca & Kuipers, 1999). In particular, caregivers who criticised the service user more distanced themselves to a greater extent (Cotton et al., 2013).

In contrast, optimistic coping has been linked to lower levels of psychological distress in caregivers of service users with a first episode of psychosis (Cotton et al., 2013). Strategies such as positive reframing may be important in buffering the distress experienced by caregivers and the attributions they may make regarding their relative’s control of their illness (Fortune et al., 2005). Caregivers who engaged in connection coping and therefore sought help or advice may also have lower levels of distress (Onwumere et al., 2011). Following Kuiper et al.’s (2010) model, those who seek help for their relatives from those around them during an acute episode of illness may have stronger relationships with their relatives and experience less burden and isolation as a result. However, it may also be indicative of a need for control and, therefore, emotional overinvolvement (Kuipers & Bebbington, 1988).

In summary, coping is a crucial link to understanding the caregiver’s experience. As outlined above, poorer coping is linked to caregivers’ negative appraisals of caregiving, psychological distress, burden and expressed emotion. Aside from these constructs, it may also be linked to a number of demographic factors. For example, there is inconclusive evidence within the literature detailing whether coping mechanisms are linked to caregiver age and gender (Chadda, Singh, & Ganguly, 2007; Chakrabarti & Gill, 2002; Mackay & Pakenham, 2012; Magliano, Fadden, Madianos, et al., 1998; Onwumere et al., 2011; Scazufca & Kuipers, 1999). According to Nehra, Chakrabarti, Kulhara, and Sharma (2005), female caregivers of service users with bipolar disorder or schizophrenia tended to adopt problem-focused coping strategies. Additionally, Goossens et al. (2008) found that avoidant methods of coping were more frequently adopted by male caregivers. These two studies, however, directly contradict each other with regard to whether males or females seek more social support. A debate exists as to whether the service user’s diagnosis may account for differences in coping strategies between caregivers with disparate accounts supporting either conclusion (Mackay & Pakenham, 2012; Nehra et al., 2005; Scazufca & Kuipers, 1999). There are also indications that coping mechanisms may change over time and stage of illness (Cotton et al., 2013). For example, Gerson et al. (2011) found that caregivers tended to use avoidance predominantly at the early phase of their relative’s illness and Parabiaghi et al. (2007) found that caregivers employ more efficient coping strategies as time passes. Finally, there are early indications
that higher levels of functioning in service users are connected to the use of problem-solving coping in caregivers.

The aim of this chapter was to firstly define the term ‘caregiver’ within the context of this thesis. It then progressed to introduce a theoretical paradigm, the stress-coping framework, that will underpin our understanding of caregiving throughout the thesis. Using this framework, we examined how contextual variables, particularly burden, appraisal and coping affect caregiving. Finally, this chapter will conclude by informing the reader of what this thesis seeks to examine via a series of suggested hypotheses. The following chapter will then address how our suggested hypotheses will be tested.
Figure 1. 
Diagram depicting direction of relationship between perception of admission, coping strategy, burden, psychological distress, expressed emotion and problem-solving within a stress-coping theoretical framework.
2.3 The present study

This thesis examines the caregiver’s experiences of their relative’s admission to a psychiatric hospital. Its primary focus is to better understand the caregiver’s perception (appraisal) of coercion in the service user’s admission. Most crucially, this thesis will examine whether the service user’s legal status at admission has any bearing on the caregiver’s perspective. This is imperative as perceived coercion is normally evaluated according to whether service users are admitted involuntarily or voluntarily within the literature.

This thesis will also explore how caregivers experience their relative’s mental illness. Although the caregivers’ perspective of the admission is central to this thesis, it is necessary to understand whether there are contextual and psychological factors related to caregiving that may affect this perspective. A stress-coping paradigm will be used to understand how caregivers perceive their experience of caregiving. Additionally, it will tentatively examine whether the service user’s legal status has any bearing on these factors.

In this thesis, we estimate that the arduous nature of involuntary admission may contribute to higher levels of perceived coercion and pressures and lower levels of perceived procedural justice in caregivers and that caregivers’ will hold more positive accounts of the admission. We estimate that these perceptions, in turn, will be linked to higher levels of caregiver burden, psychological distress and expressed emotion. Furthermore, we estimate that more maladaptive coping mechanisms will be linked higher levels of burden, psychological distress and expressed emotion in caregivers.
In this study, our key hypotheses were that:

1. Caregivers of involuntarily admitted service users would reveal higher levels of perceived coercion and perceived pressures and lower levels of procedural justice than caregivers of voluntarily admitted service users.
2. Caregivers would perceive the admission as less coercive, less pressured and more procedurally just than service users, reflective of a second-hand experience.
3. Caregivers of involuntarily admitted service users would feel more burdened and psychologically distressed than caregivers of voluntarily admitted service users.
4. Caregivers of involuntarily admitted service users would project higher levels of expressed emotion than caregivers of voluntarily admitted service users.
5. Caregivers of involuntarily admitted service users would adopt more emotion-focused than problem-focused coping strategies than caregivers of voluntarily admitted service users.
6. Caregivers’ appraisal of the admission (perceived coercion, pressures & procedural justice) would be linked to caregiver burden and psychological distress.

Three subsidiary hypotheses also resulted from using a stress-coping theoretical model. These hypothesise that:

1. Caregiver burden would predict caregivers’ psychological distress, expressed emotion and coping strategies.
2. Caregivers’ coping strategies would predict psychological distress and expressed emotion.
3. Social problem-solving ability would be higher in the caregivers of those who were voluntarily admitted and that, as a coping strategy, social problem-solving would be linked to burden, psychological distress and expressed emotion.
Chapter Three

Methodology

This chapter addresses the quantitative methodology adopted to address the hypotheses proposed in the previous chapter. It primarily describes who took part in the study, where and how the study occurred and what assessments were used to measure the extent to which the hypotheses were supported. Finally, it provides insight into the ethical considerations of the study and outlines the statistical analysis that will be used to evaluate the data obtained.

3.1 Recruitment

Participants consisted of caregivers and service users who were involuntarily or voluntarily admitted to an acute in-patient psychiatric unit in one of five hospitals across Ireland. Service users were initially interviewed at baseline between May, 2010 and May, 2011. They were subsequently interviewed at discharge between May, 2011 and April 2013. Caregivers were interviewed between March, 2012 and August, 2013. Participants were recruited from two concurrent studies that examined the service user’s experience of admission in Ireland: The ‘Service User's Perspectives of their Admission’ (SUPA) study (O'Donoghue et al., 2013) and the ‘Prospective Evaluation of the Operation and Effects of the Mental Health Act from the viewpoints of Service Users and Health Professionals’ study. The former was conducted in South-East Dublin and North Wicklow and involved both involuntarily and voluntarily admitted service users. The latter was conducted in Galway and Roscommon and included involuntarily admitted individuals and individuals who were subsequently not detained under the Mental Health Act (MHA) 2001.

As service users were interviewed prior to their caregivers, the inclusion or exclusion criteria for caregivers stemmed from those applied to service users. Service users were excluded if they could not provide informed consent, had a diagnosis of dementia or a
moderate to severe intellectual disability that rendered them unable to participate in the study. Service users who received an axis II (DSM-IV) primary diagnosis of a personality disorder or substance addiction disorder were excluded from the present study, as these individuals cannot be admitted involuntarily under the MHA 2001. Caregivers who were aged less than 18 years old at the time of interview or had a severe intellectual disability that impeded their ability to consent were similarly excluded from participation in the study. Our participant recruitment process is depicted below in Flow Diagram 1.

Finally, a power analysis using G*Power Version 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) was conducted to understand the minimum sample size needed to examine differences between involuntarily and voluntarily admitted caregivers and between caregivers and service users. This analysis identified a requirement for a minimum of 118 participants in total, 59 participants per group (involuntarily admitted vs voluntarily admitted), in order for findings to be sufficiently powered for statistical analysis (90% power at the 5% significance level).
3.2 Procedure

Our informed consent process consisted of three steps. Firstly, service users provided written consent to participate in either study when interviewed during a follow-up assessment a year after admission. Following this, they provided consent for their caregiver to be contacted. Caregivers were then approached by one of two members of the research team and information on the study was provided. For interested caregivers, a meeting with a researcher was arranged and informed written consent was sought. Finally, the caregiver provided informed consent to participate in the caregiver study. These interviews occurred in hospital, in the associated psychiatry outpatient clinic or within the caregiver’s home depending on the preference of the caregiver.
3.3 Participants

A total of 66 caregivers and 66 service users were paired to take part in this study. Our sample of caregivers was predominantly female (n=44, 67%) and the mean age of all caregivers was 55 years (SD±15 years). The majority of caregivers were parents (n=37, 56%), 17% (n=11) were spouses or partners, 14% (n=9) were siblings, 9% (n=6) were children and 4% (n=3) were other relatives. Caregiver interviews took place between March, 2012 and August, 2013.

Fifty-three percent of service users (n=35) were male. The mean age of all service users was 39 years (SD±13 years). The majority of our sample was single (n=42, 64%). The mean Global Assessment of Functioning (GAF) score for service users was 30.94 (SD±12.55). A total of 71% (n=47) of service user participants were involuntarily admitted and, of those admitted involuntarily, 28% (n=13) were initially admitted voluntarily but were then subsequently detained involuntarily (under Form 13). Of those voluntarily admitted, 8% (n=5) had been brought to hospital under the mental health act 2001 but the involuntary admission was not completed. The characteristics of caregivers and service users are presented in Table 2.

Table 2

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Caregivers n = 66</th>
<th>Service Users n = 66</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22(33)</td>
<td>35(53)</td>
</tr>
<tr>
<td>Female</td>
<td>44(67)</td>
<td>31(47)</td>
</tr>
<tr>
<td><strong>Age (M ± SD)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>55±15</td>
<td>39±13</td>
</tr>
<tr>
<td>Male</td>
<td>51±17</td>
<td>35±11</td>
</tr>
<tr>
<td>Female</td>
<td>55±16</td>
<td>43±13</td>
</tr>
<tr>
<td><strong>Marital Status n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>5(8)</td>
<td>42(64)</td>
</tr>
<tr>
<td>Married/Relationship</td>
<td>49(73)</td>
<td>16(24)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>6(9)</td>
<td>8(12)</td>
</tr>
<tr>
<td>Widowed</td>
<td>6(9)</td>
<td>0(0)</td>
</tr>
</tbody>
</table>
3.4 Instruments

Both caregivers and service users took part in a set of assessments. As this thesis primarily assesses the experiences of caregivers, this chapter will firstly present the measures used in caregiver interviews.

**Caregivers**

Caregivers were asked to recall their experiences of their relative’s admission to hospital and share their experiences as a caregiver. Within these accounts, caregivers often offered both positive and negative impressions of the admission as well as their opinions on the use of certain psychiatric practices. Caregivers’ descriptions of their experiences prior to, during and following admission were qualitatively recorded as notes. We used the following quantitative tools for data collection:

*Adapted MacArthur Admission Experience Survey (AES)* (Gardner et al., 1993)

The MacArthur Admission Experience Interview (short form) is the primary measure of perceived coercion in a mental health service user sample. It is composed of thirteen statements divided into three sub-scales; perceived coercion, perceived pressures and procedural justice. In the original interview the statements are directed towards service users and the answer options provided are ‘true’ or ‘false’. However, as there is no scale for assessing perceived coercion, perceived pressures and procedural justice in caregivers, the interview was adapted to fit a caregiver population. Statements in all three sections were redirected to ask caregivers whether they perceived that their relative experienced coercion at admission. In the perceived coercion section, questions were about choice, influence, freedom or control at the time of their admission and on whether hospitalisation was their idea. For example, the original statement ‘I chose to come into the hospital’ aimed at service users was converted into a question ‘Did your relative choose to come into hospital?’ for caregivers. In the perceived pressures section of the questionnaire, questions were about being talked into, threatened, forced or offered
Finally, with regard to procedural justice, questions were about whether service users were treated respectfully and fairly at the time of their admission. We also asked service users and carers to illustrate if they perceived that the other people involved in the admission seriously considered their point of view and whether they acted out of concern. Similarly to the original MacArthur Admission Experience Interview, the three subscales were separately marked 0-5 for perceived coercion, 0-4 for perceived pressures and 0-12 for procedural justice. Higher scores in perceived coercion and perceived pressures were negative as they indicated a higher level of perceived coercion and pressures. However, higher scores in procedural justice indicated that service users’ and carers perceived the admission as procedurally just and were therefore positive. Although there is no clinical cut-off score, scores from other studies tend to range from 2.47-2.90 for perceived coercion, approximately 1.1 for perceived pressures and 1.1-1.7 for procedural justice for in-patient service users (O'Donoghue et al., 2013; Sheehan & Burns, 2011).

Face validity and high levels of internal consistency of the MAES have been noted in a number of studies (Gardner et al., 1993; Hiday et al., 1997). A Cronbach alpha of 0.86 (Hiday et al., 1997) and an inter-item correlation of 0.65 (Nicholson, Ekenstam, & Norwood, 1996) were found when assessing the MacArthur Admission Experience Survey in a sample of in-patient service users with a dual diagnosis. One alternative validated measure, the Coercion Ladder, provides a ten step visual analogue scale of perceived coercion in mental health service users (Hoyer et al., 2002). This, however, was not used as it is a less comprehensive measure of perceived coercion as it is limited to measuring the degree of coercion, threats or pressures only.

*Involvement Evaluation Questionnaire (IEQ-EU)* (Schene, 2001)

The Involvement Evaluation Questionnaire was employed as a measure of the caregiver burden within the previous four weeks. It consisted of 27 core items divided into four sections: urging, supervision, tension and worrying. (N.B. Two sections of the IEQ-EU were not included in this study; questions pertaining to financial status and costs, and
consequences for children of individuals with mental health difficulties). Urging referred to whether caregivers encouraged service users to undertake daily activities such as washing, eating and taking prescribed medication. An example of an urging question was ‘How often during the past four weeks have you encouraged your relative to eat enough?’.

Supervision referred to whether caregivers undertook activities in which they guarded service users from committing harm to self or others. An example of a question concerning supervision was ‘How often during the past four weeks have you guarded your relative from taking illegal drugs?’. In the tension sub-category, caregivers were asked if they felt that their relationship to the service user constituted tension. An example of such was ‘How often during the past four weeks has the atmosphere been strained between you both, as a result of your relative’s behaviour?’. Finally, with regards to worrying, caregivers were asked whether they were worried about any aspect of their relative’s life. This was narrated by questions such as ‘How often during the past four weeks have you worried about the kind of help/treatment your relative is receiving?’.

Following each question, participants were asked to score the frequency that most reflected their recent situation from one of the following options: ‘never’, ‘sometimes’, ‘regularly’, ‘often’ and ‘(almost) always’. Answers were measured according to a Likert scale of 0-4 with scores ranging from 0-108.

The IEQ has been found to be a reliable instrument, with a Cronbach alpha value ranging from 0.74-0.85 for each sub-scale and 0.90 for the total score (van Wijngaarden et al., 2000). Good internal consistency and a correlation coefficient were found ($\alpha = 0.73-0.84$ and 0.80 respectively) in a study examining emotional burden in carers of individuals with brain injury (Geurtsen, Meijer, van Heugten, Martina, & Geurts, 2010). Norm score ranges for each of the four sub-sections of burden are the following: 0.88-1.86 for Tension, 0.45-1.6 for supervision, 2.3-2.9 for worrying and 1.07-2.17 for urging (Goncalves-Pereira et al., 2012; Parabiaghi et al. 2007). The upper ranges were found in caregivers of individuals with a brain injury whilst the lower ranges were more found in caregivers of psychiatric service users.
There are a number of alternative caregiving scales. The other most notable measure of caregiving, the Experience of Caregiving Inventory (ECI) assesses both positive and negative aspects of caregiving (Szmukler, Burgess, et al., 1996). It includes measurements pertaining to problems encountered with the mental health services, positive aspects to the relationship, dependency, loss, stigma, difficult behaviours and effects of the service user’s illness of the family. As it was originally constructed for caregivers of service users with a schizophrenic spectrum disorder it includes scales pertaining to negative symptoms. Although it is a well-rounded scale, the IEQ was preferred in this study as it incorporates a measure of psychological well-being.

*General Health Questionnaire-12 (GHQ-12)* (Goldberg, 1978)

The General Health Questionnaire (GHQ-12) was used to indicate whether caregivers were experiencing emotional difficulties that may have required medical attention up to four weeks before the interview. Each question measured the presence of a symptom of psychological distress according to a four point scale. Scores were marked bimodally as (0-0-1-1) with a score of 1 indicating the presence of a difficulty. Examples of items on the scale were ‘Have you recently been able to enjoy your normal day-to-day activities?’ and ‘Have you recently lost much sleep over worry?’ Participants indicated whether a certain symptom appeared in the previous four weeks with an increasing, decreasing or similar frequency to the previous months (ie. more so than usual, same as usual, less than usual, much less than usual). A score of 4 or above in the GHQ-12 acted as a significant marker of psychological distress in previous research (Tedstone Doherty, Ward, & Kartalova-O’Doherty, 2007). The GHQ-12 is viewed as an internally consistent measure of psychological distress (α = 0.87) (Hankins, 2008).

*Brief COPE* (Carver, 1997)

The Ways of Coping scale was designed by the proposers of the stress-coping framework (Folkman & Lazarus, 1980) in order to measure the coping aspects of their model. The brief COPE is a shorter version of the COPE inventory adapted from this scale. The brief
COPE is a 28-item self-report measure that assesses individuals’ methods of coping with difficult life events. This measure evaluated the presence and extent to which 14 stress responses and coping patterns appeared in an individual. These were: self distraction, active coping, denial, substance use, emotional support, instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame. Participants were instructed to think about the thoughts or activities they engaged or how they usually coped when under stress. Carers were then asked to select a response which best described their course of action for each statement: ‘I usually don’t do this at all’, ‘I usually do this a little bit’, ‘I usually do this a medium amount’ or ‘I usually do this a lot’. Items from the scale include ‘I’ve been trying to see it in a different light, to make it seem more positive’ and ‘I’ve been accepting the reality of the fact that it has happened’. Each of the 14 coping patterns was measured by means of two items. Therefore, adding each set of two items conveyed the extent to which each carer partook in a given coping mechanism. For example, items 12 and 26 both referred to substance abuse as a coping mechanism. There is no overall score for the Brief COPE. Rather, each item is scored from 1-4 according to the order of the responses listed above (ie. 1 = ‘I usually don’t do this at all’).

Each of the 14 coping styles in the Brief COPE reveal reliability values that exceed 0.50 (Carver, 1997). In studies examining coping in carers of different types of illness (ie. dementia), internal consistency and test-retest reliability for emotion-focused, problem-focused, and dysfunctional subscales was found to be good (α = 0.72, 0.84, 0.75, and r = 0.58, 0.72, 0.68; p < 0.001 respectively) (Cooper, Katona, Orrell, & Livingston, 2008). Convergent and concurrent validity for emotion-focused coping was predicted by secure attachment (β= 0.23) and by problem-focused coping (β= 0.68); dysfunctional coping by burden (β = 0.36), less secure attachment (β = -0.25) and problem-focused coping (β = 0.31; all p < 0.05).

This measure consisted of 60 items that assessed caregiver’s levels of expressed emotion in the previous three months. It was composed of four fifteen-item subscales designed to measure intrusiveness, emotional response, attitude toward illness and tolerance or expectations. Participants were asked to affirm whether they felt that each statement was a true or false reflection of their behaviour. Examples of statements were ‘I am always interfering’, ‘I say I understand if sometimes he/she doesn’t want to talk’ and ‘I insist on knowing where he/she is going’.

Each item was scored ‘1’ or ‘0’ according to a preset scoring key. A score of ‘1’ was given for each item that represented a form of expressed emotion. As presented in earlier studies, total scores were used as a marker of expressed emotion and individual scores for the four subscales were used as individual markers of intrusiveness, emotional response, attitude toward illness and tolerance (Cole & Kazarian, 1988; Hooley & Parker, 2006). A high overall score on the LEE scale identified a high level of expressed emotion from the caregiver towards the service user.

The gold standard assessment of expressed emotion is typically the Camberwell Family Interview (CFI) (Leff & Vaughn, 1985). However, it was not selected due to unavailability of training and for its time-consuming administrative and scoring properties. Another alternative assessment for expressed emotion was the Five Minute Speech Sample (Magana et al., 1986). Although this assessment would take less time to administer, it was not selected as analysis of each segment would require substantially more time and training. Nevertheless, the LEE scores for reliability of ‘perceived expressed emotion’ were $\alpha = 0.93$ in a clinical sample and $\alpha = 0.90$ in a healthy sample. Scores for internal consistency were 0.84-0.89 (Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002). Furthermore, aspects of the Level of Expressed Emotion scale have been found to be correlated with the Camberwell Family Interview. The CFI’s dimensions of warmth and critical comments were linked to the LEE’s Attitude towards Illness dimension ($r = -.41$, $r = .49$, $p < 0.05$ respectively) (Kazarian, Malla, Cole, &
Baker, 1990). Additionally, critical comments present in the CFI were linked to total scores in the LEE (r = .38, p < 0.05) (Kazarian et al., 1990).

*The Social Problem-Solving Inventory-Revised (Short form)* (D'Zurilla, Nezu, & Maydeu-Olivares, 1990)

The SPSI-R:S is the primary measure of social problem-solving within the literature. It is a 25 item instrument designed to measure general levels of social problem-solving in adults in both normal and clinical populations. Within this study, levels of social problem-solving were compared between caregivers of involuntarily and voluntarily admitted service users and examined according to whether they correlated with burden, psychological distress and expressed emotion (as per subsidiary hypothesis six). The scale measures individuals’ ability and manner of approaching and coping with problems occurring in daily life. The scale is divided into 5 further sub-scales; Negative Problem Orientation (NPO), Positive Problem Orientation (PPO), Rational Problem Solving (RPS), Impulsivity/Carelessness Style (ICS) and Avoidance Style (AS). Caregivers were asked to read each statement and judge whether each statement was ‘extremely true’, ‘very true’, ‘moderately true’, ‘slightly true’ or ‘not at all true’ of their approach to solving a problem. Sample items from this inventory were ‘Whenever I have a problem, I believe that it can be solved’, ‘Difficult problems make me very upset’ and ‘I spend more time avoiding problems than solving them’. The final score per sub-scale was derived by categorising the participant’s raw score according to their age group. Therefore, the same raw score in two individuals may elicit different final scores depending on participants’ age. Strong alpha coefficients were found in a large sample of university students: 0.92 (Negative Problem Orientation), 0.80 (Positive Problem Orientation), 0.95 (Rational Problem Solving), 0.89 (Impulsivity/Carelessness Style) and 0.89 (Avoidance Style). The adjusted goodness of fit value for structural validity was 0.89 (D’Zurilla et al., 1990). Additionally, good scores of internal consistency and reliability were found in psychiatric and medical samples (Dreer et al., 2009; Sadowski, Moore, & Kelley, 1994).
Service Users

Service users also underwent an extensive battery of tests as part of a baseline assessment for the ‘Service User’s Perspectives of their Admission’ (SUPA) study (O'Donoghue et al., 2013) and the ‘Prospective Evaluation of the Operation and Effects of the Mental Health Act from the viewpoints of Service Users and Health Professionals’ study. These two studies primarily examined perceived coercion in service users during hospital admission. Three of the measures from the two studies were included in the present study. The first of these, as reported above for caregivers, was the MacArthur Admission Experience Survey (AES). The original MacArthur Admission Experience Survey (AES) is the ‘gold standard’ measure of perceived coercion, perceived pressures and procedural justice in service users. The remaining two measures: the Structural Clinical Interview for DSM-IV Disorders (SCID) and the Global Assessment of Functioning (GAF) pertained to clinical characteristics and symptomatology.

Diagnostic and clinical information pertaining to the service user was taken from a Structural Clinical Interview for DSM-IV Disorders (SCID) (First, 1996). The SCID is a semi-structured interview assessment used to formulate a diagnoses of an Axis-I disorder. The reliability of the SCID ranges between moderate to high according to the diagnosis (Lobbestael, Leurgans, & Arntz, 2011; Zanarini, Reichman, Frankenburg, Reich, & Fitzmaurice, 2010). Higher levels of validity have been found in the SCID in comparison to other forms of clinical interviews (Basco et al., 2000). Satisfactory values of reliability for the SCID have been reported when used in clinical settings (Sonesson, Tjus, & Arvidsson, 2010).

The Global Assessment of Functioning (GAF) scale was used to determine the psychological, social and occupational level of functioning of each service user at the time of interview (American Psychiatric Association, 2000). It formed part of the assessment for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV-TR; American Psychiatric Association, 2000). Scores range from 0-100 with higher scores indicating higher levels of functioning. There is no cut-off score for this
assessment. However, scores increase by ten point increments. For example, a score of 91-100 denotes superior functioning. In contrast, a score of 50-41 refers to the presence of “serious symptoms or serious impairment in social or occupational functioning”. Finally, a score of 10-1 may warn clinicians of a “persistent danger of severely hurting self or others”. A score of 41-50 Similarly to the SCID, and as part of a diagnostic evaluation, the GAF scale has produced reports of satisfactory reliability in clinical use (Sonesson et al., 2010)

3.5 Ethical Considerations

The present study received full ethical approval from the ethical committees of Trinity College Dublin, the Hospitaller Order of St. John of God, Newcastle Hospital and Galway University Hospital (Please see Part IV, Appendices I-IX). The study was submitted for ethical approval to ensure that it conformed to ethical standards regarding informed consent, anonymity and involving caregivers and service users in research without undue coercion or pressures. Due to the sensitivity of the information entrusted by the caregivers to the researchers, a clinician who was a member of the research team was made available to all participants should they feel distressed. The purpose of this exercise was to help redirect caregivers towards the appropriate help if they felt it was needed.

3.6 Statistical Analysis

Participants’ scores were stored in an MS Access database and statistically analysed using SPSS version 21. Initial checks and analyses were conducted to examine whether the sample’s scores displayed homogeneity of variance, skewness or kurtosis. Missing data from participants were allocated a set value (99) and excluded from analysis. Descriptive analyses were conducted to determine median and interquartile ranges for each instrument within the sample.
The first two hypotheses adopted a repeated measures design to test for differences between caregivers’ and service users’ scores of perceived coercion, perceived pressures and procedural justice. Although this type of analysis is usually reserved for testing a group’s scores over time, caregiver and service user scores cannot be judged to be completely independent of each other (Bauer, Gottfredson, Dean, & Zucker, 2013). The analysis used to test the first two hypotheses was, therefore, informed by caregiver and health studies (Cleary, Freeman, Hunt, & Walter, 2006; Northouse & Swain, 1987). When examining whether differences occurred between caregivers according to legal status on all other hypotheses, independent t-tests or analyses of variance (ANOVA) were used. Eta-squared was reported as a measure of the magnitude of difference between statistically significant scores. Simple and multiple regressions were used to search for predicting variables between constructs according for subsidiary hypotheses 1-5. Finally, Pearson product correlations were produced to check for associations between variables in the sixth subsidiary hypothesis. Post-hoc tests such as chi-square tests for independence were conducted to explore for possible associations between clinical and demographic characteristics and significantly different scores. These results are presented in the next chapter.
Chapter Four

Results

This results chapter will, firstly, describe how the data were managed. Secondly, it will convey which preliminary descriptive analyses were performed prior to examining how our data fit our suggested hypotheses. Finally, it will detail the findings of our main and subsidiary hypotheses and state whether these were supported or not.

4.1 Initial Data Management

The data obtained from caregiver and service user questionnaires were tested for normality. Quartile-Quartile plots and Kolmogorov-Smirnov tests were conducted for each subscale within each measure. Most data were not normally distributed. The data were screened for whether missing data was random. Finally, the data was checked for outliers that may have affected the scores from each instrument.

4.2 Descriptive Analysis

Following the above initial management of the data, caregivers’ and service users’ demographic and diagnostic characteristics were described according to the service user’s legal status at admission. Chi-square tests demonstrated that the service user’s legal status at admission was not affected by demographic factors such as the gender or marital status of caregivers or service users, diagnostic factors such as the service user’s diagnosis, or alcohol/drug comorbidities, nor social factors such as the type of relationship shared between caregivers and service users and whether the caregiver and service user lived in the same household (see Table 3 below). Correlations demonstrated that legal status was not linked to the caregivers’ or service users’ age (Table 3). The only variable linked to legal status was the service users’ level of functioning (GAF Score). In this study, higher
levels of functioning and alcohol comorbidity in service users’ were linked to voluntary status at admission (Table 3).

Unfortunately, we do not hold information pertaining to those who did not consent and, therefore, cannot draw comparisons based on their characteristics. However, a systematic review examining such characteristics could not decisively conclude that either age or disability were linked to health studies’ participation due to contradictory evidence (Kho et al., 2008). However, in the same review and similarly to our results, those who consented tended to be male.

Table 3

<table>
<thead>
<tr>
<th>Characteristic (Χ²/FET)</th>
<th>Caregiver</th>
<th>Service User</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>1.69</td>
<td>1.10</td>
</tr>
<tr>
<td>Age</td>
<td>0.01§</td>
<td>-.13§</td>
</tr>
<tr>
<td>Marital Status</td>
<td>2.24</td>
<td>1.49</td>
</tr>
<tr>
<td>Type of Relationship</td>
<td>3.88</td>
<td></td>
</tr>
<tr>
<td>Functioning (GAF Score)</td>
<td></td>
<td>12.82**</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td>1.15</td>
</tr>
<tr>
<td>Drug Comorbidity</td>
<td></td>
<td>.02</td>
</tr>
<tr>
<td>Alcohol Comorbidity</td>
<td></td>
<td>4.93*</td>
</tr>
</tbody>
</table>

*p ≤ .05; **p ≤ .01; § correlation; GAF: Global Assessment of Functioning
FET: Fisher’s exact test

4.3 Hypothesis Testing

1. **Hypothesis One: That caregivers would perceive the admission as less coercive, less pressured and more procedurally just than service users, reflective of a second-hand experience.**

Our first hypothesis was tested using a repeated measures design. As conveyed in the methodology, this design was adopted as it is likely that caregivers and service users influence each other’s perceptions regarding the admission. These perceptions may, therefore, not be formed or held as independent of each other. This hypothesis was tested in three phases. All caregivers’ scores were firstly compared against the service users’.
Secondly, caregivers’ scores were compared to the service users’ according to the service user’s legal status (involuntarily admitted or voluntarily admitted). If we found a significant difference, these scores were then further analysed according to their exact status at admission: involuntarily admitted, initially voluntarily admitted and subsequently detained, brought to hospital involuntarily but not subsequently detained or voluntarily admitted. Legal status was firstly examined according to the two groups (involuntarily admitted vs voluntarily admitted) as the scores of those who were brought to hospital involuntarily and not subsequently detained were omitted from more complex analyses due to a small sample size. As the MacArthur Admission Experience Survey was composed of three subscales, the data presented followed the structure of the instrument. The findings of the first of these subscales, perceived coercion, are presented below.

**Perceived Coercion**

The median score of perceived coercion reported by caregivers was 1 (Interquartile Range = 1, 3) and 5 (Interquartile Range = 3, 5) for service users. A Wilcoxon signed-rank test showed that caregivers perceived the service user’s admission as less coercive than service users \(z = -5.32, p \leq .00, r = 0.46\). Involuntarily admitted service users (median = 5, interquartile range = 4-5) reported higher levels of perceived coercion compared to their caregivers \(median = 1, interquartile range = 1, 1, z = -5.84, p \leq .00, r = 0.60\). There was no difference in the level of perceived coercion reported between voluntarily admitted service users \(median = 3, interquartile range = 1, 5\) their caregivers \(median = 3, interquartile range = 1, 4, z = -0.43, p > .05, p = .07, r = .05\).
<table>
<thead>
<tr>
<th>Measure (Median ± IQR)</th>
<th>Caregivers</th>
<th>Service Users</th>
<th>z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Coercion</td>
<td>1 (1-3)</td>
<td>5 (3-5)</td>
<td>-5.32 **</td>
</tr>
<tr>
<td>Involuntary</td>
<td>1 (1-1)</td>
<td>5 (4-5)</td>
<td>-5.84 **</td>
</tr>
<tr>
<td>Voluntary</td>
<td>3 (1-4)</td>
<td>3 (1-5)</td>
<td>-4.3</td>
</tr>
<tr>
<td>Involuntary (Form 6)</td>
<td>1 (1-1)</td>
<td>5 (4-5)</td>
<td>-5.04 **</td>
</tr>
<tr>
<td>Involuntary (Form 13)</td>
<td>1 (1-3)</td>
<td>5 (4-5)</td>
<td>-3.08 **</td>
</tr>
<tr>
<td>Holding Power</td>
<td>3 (1-4)</td>
<td>4 (3-5)</td>
<td>-1.51</td>
</tr>
<tr>
<td>Voluntary</td>
<td>3 (1-4)</td>
<td>2 (1-4)</td>
<td>-1.5</td>
</tr>
<tr>
<td>Involuntary (Form 6)</td>
<td>1 (1-2)</td>
<td>1 (1-2)</td>
<td>-1.26</td>
</tr>
<tr>
<td>Involuntary (Form 13)</td>
<td>2 (1-2)</td>
<td>1 (1-2)</td>
<td>-0.49</td>
</tr>
<tr>
<td>Perceived Pressures</td>
<td>1 (1-2)</td>
<td>1 (1-2)</td>
<td>-1.74</td>
</tr>
<tr>
<td>Involuntary</td>
<td>2 (1-2)</td>
<td>2 (1-2)</td>
<td>0.00</td>
</tr>
<tr>
<td>Voluntary</td>
<td>0 (0-2)</td>
<td>1 (0-2)</td>
<td>-1.7</td>
</tr>
<tr>
<td>Procedural Justice</td>
<td>15 (12-16)</td>
<td>12 (8-16)</td>
<td>-2.95 **</td>
</tr>
<tr>
<td>Involuntary (Form 6)</td>
<td>14 (10-15)</td>
<td>11 (3-15)</td>
<td>-2.05 *</td>
</tr>
<tr>
<td>Involuntary (Form 13)</td>
<td>16 (15-16)</td>
<td>14 (8-16)</td>
<td>-2.19 *</td>
</tr>
<tr>
<td>Holding Power</td>
<td>16 (15-16)</td>
<td>15 (14-16)</td>
<td>-1.69</td>
</tr>
</tbody>
</table>

* = p ≤ .05; ** = p ≤ .001, IQR: Interquartile Range

A two-way mixed design analysis of variance was conducted to explore whether specific legal status (involuntary admission, voluntary admission and subsequent detention, involuntary arrival to hospital but no involuntary admission or voluntary admission) at admission (between-subjects) had an effect on caregivers’ and service users’ responses of perceived coercion (within-subjects). This form of analysis was proposed, as there is no non-parametric equivalent. Legal status was restricted to three categories; involuntary admission (service users admitted under form 6), involuntary admission following an initial voluntary admission (service users classified under form 13) and voluntary
admission. Those who were brought to hospital involuntarily and subsequently not admitted under the Mental Health Act 2001 were excluded, as there were too few in this category for this analysis (n = 4). There was a significant main effect between the respondents, [Wilks’ λ = .61, f (1,58) = 37.42, p ≤ .001, ηp2 = .39], which indicated that perceived coercion differed between caregivers and service users. There was no significant between-subjects effect between the respondents’ scores of perceived coercion and legal status [f (2,58) = .68, p > .05, ηp2 = .02], suggesting that perceptions of coercion between caregivers and service users did not differ according to legal status. However, we found a significant interaction between caregivers’ and service users’ appraisals of perceived coercion and legal status [Wilks’ λ = .64, f (2, 58) = 16.68, p ≤ .001, ηp2 = .37].

**Figure 3**

*Significant interaction effect between Perceived Coercion scores and Legal Status*
The median score of perceived pressures reported by caregivers and service users was the same (median = 1, interquartile range = 1, 2). A Wilcoxon signed-rank test showed that there was no difference between the level of perceived pressures reported by caregivers and service users (z = -1.26, p > .05, r = .11). When participants’ scores were divided according to legal status, we did not find differences between those admitted involuntarily and their caregivers (z = - .49, p > .05, r = .05). There was also no difference in levels of perceived pressures between voluntarily admitted service users and their caregivers (z = -1.70, p > .05, r = .28). Therefore, no further analysis was performed.

The median score of procedural justice was 15 (Interquartile range = 12, 16) in caregivers and 12 (Interquartile range = 8, 16) in service users. A signed-rank test showed that caregivers perceived the service user’s admission as less coercive than service users (z = -2.95, p ≤ .00, r = .26). When separating the groups according to legal status, a significant difference was found between those admitted involuntarily and their caregivers (z = -2.05, p ≤ .05, r = .21). There was also a significant difference between voluntarily admitted service users’ accounts of procedural justice and their caregivers (z = -2.11, p ≤ 0.05, r = .34).

A two-way mixed analysis of variance was used to explore whether differences occurred between caregivers’ and service users’ scores of procedural justice (within-subjects) and specific legal status (between-subjects; involuntary admission, voluntary admission and subsequent detention, involuntary arrival to hospital but no involuntary admission or voluntary admission). There was a significant main effect between scores of procedural justice in caregivers and service users [Wilks’ λ = .93, f (1, 57) = 4.34, p ≤ .05, ηp2 = .07], which indicated that these scores differed between the two groups. A significant between-subjects effect was observed between procedural justice scores and legal status [f (2, 57) = 5.55, p ≤ .01, ηp2 = .16], indicating that procedural justice scores were impacted by legal status. Differences in scores of procedural justice were found using a Bonferroni correction. These were located between service users and caregivers of those involuntarily admitted (M = -2.57 ± .81) and voluntarily admitted (p = .01), and in caregivers and service users who were detained following an initial voluntary admission.
(M = 2.64 ± .98) versus those who entered hospital voluntarily and their caregivers (p ≤ .05). Thus, those who entered and remained in hospital voluntarily and their caregivers felt that the admission was more procedurally just than those who were brought to hospital under the Mental Health Act or were detained following an initial voluntary admission. There was no interaction effect between scores of procedural justice in caregivers and service users according to their legal status [Wilks’ λ = .996, f (2, 57) = .10, p > .05, ηp² = .00].

**Figure 4**

*Significant interaction effect between Procedural Justice scores and Legal Status*

*Involvement in Admission*

Caregivers acted as applicants for the commencement of the involuntary admission in 47% (n = 22) of cases of involuntary admissions. These caregivers (median = 1, interquartile range = 1-1) reported a lower level of perceived coercion of the admission compared to the service users (median = 5, interquartile range = 4-5, z = -4.11, p ≤ .00, r = .88). This relationship was not observed for perceived pressures (z = -1.17, p > .05, r = .25) or procedural justice (z = -1.05, p > .05, r = .22) between applicants and service users.
2. **Hypothesis Two:** That caregivers of involuntarily admitted service users would reveal higher levels of perceived coercion and perceived pressures and lower levels of procedural justice than caregivers of voluntarily admitted service users.

The second hypothesis was tested in two phases. In the first phase, the scores of caregivers of involuntarily admitted service users were compared to those of caregivers of voluntarily admitted service users by means of a Mann-Whitney U test. Those that we found to be significant were further analysed according to specific legal status: involuntarily admitted under form 6, involuntarily admitted following an initial voluntary admission under form 13 and voluntary admission. Those who were brought to hospital involuntarily and subsequently not admitted under the Mental Health Act 2001 were excluded, as there were too few in this category for this analysis (n = 4).

The median score for perceived coercion was 1 in caregivers of involuntarily admitted service users (interquartile range = 1, 1) and 3 (interquartile range = 1, 4) in caregivers of voluntarily admitted service users. A Mann-Whitney U test showed that caregivers of voluntarily admitted service users perceived their relative’s admission as more coerced than caregivers of those admitted involuntarily (U = 689, \( p \leq .00 \), \( r = .47 \)). Tukey’s Honest Significant Difference was used on these results to indicate where differences in levels of perceived coercion lay within this group. Within our caregiver group, a significant difference was found between caregivers of those admitted involuntarily (\( M = 1.18 \), SD = .72) and voluntarily (\( M = 2.71 \), SD = 1.33, \( p \leq .001 \)), with the latter perceiving lower levels of coercion at admission. As an addendum, within the service user group, individuals admitted involuntarily (\( M = 4.29 \), SD = 1.45) and those admitted voluntarily but subsequently detained (\( M = 4.08 \), SD = 1.66) displayed higher levels of perceived coercion than those who were admitted and remained in hospital voluntarily (\( M = 2.29 \), SD = 1.94, \( p \leq .05 \)).

The median score for perceived pressures was 2 in caregivers of involuntarily admitted service users (interquartile range = 1, 2) and 0 (interquartile range = 0, 2) in caregivers of
voluntarily admitted service users. A Mann-Whitney U test showed that caregivers of involuntarily and voluntarily admitted service users differed in the perceptions of pressures of their relative’s admission ($U = 228, p \leq .00, r = .41$). However, this relationship was not demonstrated in the mixed ANOVA according to specific legal status.

The median score for procedural justice was 14 in caregivers of involuntarily admitted service users (interquartile range = 10, 15) and 16 (interquartile range = 15, 16) in caregivers of voluntarily admitted service users. A Mann-Whitney U test showed that caregivers of involuntarily admitted service users perceived their relative’s admission as more procedurally just than those voluntarily admitted ($U = 619, p \leq .01, r = .33$). The findings of the two-way mixed ANOVA conducted to test our first hypothesis also revealed differences in procedural justice between caregivers. Tukey’s Honest Significant Difference was used on these results to indicate where differences in levels of procedural justice lay within this group. Within our caregiver group, caregivers of those admitted involuntarily ($M = 12.97, SD = 3.08$) reported higher levels of procedural justice than those admitted voluntarily ($M = 15.29, SD = 1.27, p \leq .05$).

3. **Hypothesis Three: That caregivers of involuntarily admitted service users would feel more burdened and psychologically distressed than caregivers of voluntarily admitted service users.**

The median level of burden overall was 13.00 (interquartile range = 6.00, 22.00). In caregivers of involuntarily admitted service users this score was 12 (IQR 6, 21) and in voluntarily admitted service users it was 16 (IQR 5, 34). A Mann-Whitney U test found no significant difference in levels of burden between caregivers of those admitted involuntarily and voluntarily ($U = 328, p = .18, r = .17$). The Involvement Evaluation Questionnaire scores were then further examined according to its four sub-scales: Urging, Supervision, Tension and Worrying. The median scores for each sub-scale are reported in Table 4. A Kruskal-Wallis test was conducted to test for significant differences between each sub-scale according to legal status. We found no statistical difference in urging...
[H(1) = .57, p > .05, r = .07], tension [H(1) = .02, p > .05, r = .00] and worrying [H(1) = 1.43, p > .05, r = .02]. However, a significant difference was found in the level of supervision displayed between caregivers [H(1) = 9.2, p ≤ .00]. Caregivers of voluntarily admitted service users (median = 2, interquartile range = 0-3) supervised their relative to a greater extent than caregivers of involuntarily admitted service users (median = 0, interquartile range = 0-0). The scores revealed a moderate effect size (r = .38).

Table 5
Median scores of Involvement Evaluation Questionnaire sub-scales and General Health Questionnaire according to legal status

<table>
<thead>
<tr>
<th>Measure (Median, IQR)</th>
<th>Total</th>
<th>Involuntary</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total IEQ</td>
<td>13 (6-22)</td>
<td>12 (6-21)</td>
<td>16 (5-34)</td>
</tr>
<tr>
<td>Urging</td>
<td>3 (1-8)</td>
<td>3 (1-6)</td>
<td>4 (0-3)</td>
</tr>
<tr>
<td>Supervision</td>
<td>0 (0-2)</td>
<td>0 (0-0)</td>
<td>2 (0-3)</td>
</tr>
<tr>
<td>Tension</td>
<td>3 (1-6)</td>
<td>3 (1-6)</td>
<td>2 (0-6)</td>
</tr>
<tr>
<td>Worrying</td>
<td>5 (2-8)</td>
<td>5 (2-7)</td>
<td>7 (3-10)</td>
</tr>
<tr>
<td>Total GHQ</td>
<td>1 (0-3)</td>
<td>1 (0-3)</td>
<td>0 (0-1)</td>
</tr>
</tbody>
</table>

IEQ: Involvement Evaluation Questionnaire, GHQ: General Health Questionnaire
IQR: Interquartile Range

Fifteen percent of participants (n=9) reported high levels of distress (defined as a score of 4 or greater on the GHQ-12). The median score of psychological distress was 1.00 (IQR 0.00, 3). The median score of psychological distress in caregivers of involuntarily admitted service users was 1.00 (IQR 0, 3) and in voluntarily admitted service users it was 0 (IQR 0, 1). Caregivers of involuntarily admitted or voluntarily admitted service users did not significantly differ in their levels of psychological distress (U = 302, p = .19).
4. **Hypothesis Four:** That caregivers of involuntarily admitted service users would report higher levels of expressed emotion than caregivers of voluntarily admitted service users.

The median score of expressed emotion was 7 (interquartile range = 4-9). In caregivers of those admitted involuntarily, this figure was also 7 (interquartile range = 4-9). The median score of expressed emotion in the caregivers of those admitted voluntarily was 6 (interquartile range = 4, 11). A Mann-Whitney U test was conducted to examine whether statistical differences occurred between caregivers on expressed emotion. We found no significant difference in expressed emotion overall between caregivers of involuntarily and voluntarily admitted service users (U = 285, p > .05). The LEE scale was then divided according to four sub-scales: intrusiveness, emotional response, attitude and tolerance. A Kruskal-Willis test found no significant difference between caregivers of involuntarily and voluntarily admitted service users on intrusiveness [H (1) = .61, p > .05], attitude [H (1) = .03, p > .05], or tolerance [H (1) = 3.00, p > .05]. Nevertheless, a significant difference was found in the emotional response displayed by the caregivers of involuntarily (median = 3, interquartile range = 2, 4) and voluntarily admitted service users with caregivers of involuntarily admitted showing a higher degree of emotional response [median = 2, interquartile range = 1, 3; H(1) = 4.93, p ≤ .05, ηp2 = .10].

**Table 6**

<table>
<thead>
<tr>
<th>Measure (Median, IQR)</th>
<th>Total</th>
<th>Involuntary</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total LEE</td>
<td>7 (4-9)</td>
<td>7 (4-9)</td>
<td>6 (4-11)</td>
</tr>
<tr>
<td>Intrusiveness</td>
<td>2 (0-3)</td>
<td>2 (0-3)</td>
<td>2 (1-4)</td>
</tr>
<tr>
<td>Emotional Response</td>
<td>2 (2-4) *</td>
<td>3 (2-4)</td>
<td>2 (1-3)</td>
</tr>
<tr>
<td>Attitude</td>
<td>1 (0-1)</td>
<td>1 (0-2)</td>
<td>1 (0-1)</td>
</tr>
<tr>
<td>Tolerance</td>
<td>1 (0-2)</td>
<td>0 (0-2)</td>
<td>1 (0-3)</td>
</tr>
</tbody>
</table>

*p ≤ .05, LEE: Level of Expressed Emotion, IQR: Interquartile Range
5. Hypothesis Five: That caregivers of involuntarily admitted service users would adopt more emotion-focused than problem-focused coping strategies than caregivers of voluntarily admitted service users.

The median score for each coping style is reported in Table 6. A Kruskal-Wallis test was carried out to observe whether differences occurred between caregivers of involuntarily and voluntarily admitted service users in all 14 coping styles. We did not find a significant difference according to legal status in any of the coping styles as shown in table 6 below.
Table 7

Median Scores for the Brief COPE scale for caregivers according to service users’ legal status (Involuntary vs Voluntary).

<table>
<thead>
<tr>
<th>COPE (Median, IQR)</th>
<th>All Caregivers</th>
<th>Involuntary</th>
<th>Voluntary</th>
<th>X²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Distraction</td>
<td>7 (2-8)</td>
<td>7 (4-8)</td>
<td>4 (2-8)</td>
<td>3.00</td>
</tr>
<tr>
<td>Active Coping</td>
<td>5 (2-7)</td>
<td>5 (2-7)</td>
<td>5 (2-7)</td>
<td>.02</td>
</tr>
<tr>
<td>Denial</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>2.29</td>
</tr>
<tr>
<td>Substance Use</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>.98</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>2 (2-4)</td>
<td>8 (4-8)</td>
<td>4 (2-8)</td>
<td>3.42</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>5 (2-8)</td>
<td>6 (2-8)</td>
<td>4 (2-8)</td>
<td>1.82</td>
</tr>
<tr>
<td>Behavioral Disengagement</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>2 (2-2)</td>
<td>.41</td>
</tr>
<tr>
<td>Venting</td>
<td>2 (2-4)</td>
<td>2 (2-4)</td>
<td>2 (2-4)</td>
<td>.00</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>4 (2-7)</td>
<td>4 (2-8)</td>
<td>4 (2-7)</td>
<td>.15</td>
</tr>
<tr>
<td>Planning</td>
<td>2 (2-5)</td>
<td>2 (2-5)</td>
<td>2 (2-5)</td>
<td>.45</td>
</tr>
<tr>
<td>Humor</td>
<td>2 (2-4)</td>
<td>2 (2-4)</td>
<td>2 (2-4)</td>
<td>.13</td>
</tr>
<tr>
<td>Acceptance</td>
<td>8 (7-8)</td>
<td>8 (5-8)</td>
<td>8 (7-8)</td>
<td>.62</td>
</tr>
<tr>
<td>Religion</td>
<td>2 (2-5)</td>
<td>2 (2-5)</td>
<td>3 (2-6)</td>
<td>.26</td>
</tr>
<tr>
<td>Self Blame</td>
<td>2 (2-4)</td>
<td>3 (2-4)</td>
<td>2 (2-4)</td>
<td>.23</td>
</tr>
</tbody>
</table>

*p ≤ .05, COPE: Coping Inventory, IQR: Interquartile Range
6. Hypothesis Six: That caregivers’ appraisal of the admission (perceived coercion, pressures & procedural justice) would predict caregiver burden and psychological distress.

A Spearman’s rank correlation was used to determine whether caregiver accounts of perceived coercion, perceived pressures and procedural justice were related to caregiver burden. Both perceived coercion and perceived pressures were not linked to scores of caregiver burden \( r (62) = 0.16, p > 0.05 \); \( r (62) = 0.05, p > 0.05 \) respectively. However, procedural justice was found to be significantly linked to caregiver burden \( r (62) = -0.27, p < 0.05 \). Therefore, an increase in caregiver burden was associated with a decrease in scores of procedural justice. When the only significant value, procedural justice, was examined according to the service user’s legal status, we found that procedural justice in the caregivers of those who were involuntarily admitted was linked to caregiver burden \( r (43) = -0.41, p < 0.05 \). Again, an increase in caregiver burden was associated with a decrease in scores of procedural justice in caregivers of those who were involuntarily admitted. This was not found for caregivers of those admitted voluntarily \( r (18) = -0.28, p > 0.05 \).

A second Spearman’s rank correlation was used to determine whether caregiver accounts of perceived coercion, perceived pressures and procedural justice were related to psychological distress. Both perceived coercion and perceived pressures were not linked to scores of psychological distress \( r (60) = -0.17, p > 0.05 \); \( r (60) = 0.06, p > 0.05 \) respectively. Nevertheless, caregivers’ levels of distress were correlated with their perceptions of procedural justice with moderate effect size \( r (60) = -0.34, p < 0.05 \). Here, an increase in psychological distress was linked with a decrease in scores of procedural justice. When procedural justice scores were examined according to the service user’s legal status, we found a link between procedural justice and psychological distress in the caregivers of involuntarily admitted service users \( r (43) = -0.35, p < 0.05 \). Similarly to above, an increase in psychological distress was related to lower scores of procedural justice with moderate effect size. This trend was not present in the scores of caregivers of voluntarily admitted service users \( r (17) = -0.13, p > 0.05 \).

A multiple regression was used to assess whether the four sub-scales of burden (Urging, Supervision, Tension and Worrying) could act as predictors of psychological distress in caregivers. Levels of caregiving and burden accounted for 16% of the variability in scores of psychological distress, \( f(4, 55) = 2.56, p \leq .05 \). The model revealed that worrying was a statistically significant predictor of psychological distress (\( \beta = .40, p \leq .05 \)). Therefore, an increase in levels of worrying was associated with an increase in psychological distress.

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>10.28</td>
<td>.88</td>
<td>.03</td>
</tr>
<tr>
<td>Urging</td>
<td>.02</td>
<td>.11</td>
<td>.03</td>
</tr>
<tr>
<td>Supervision</td>
<td>-.17</td>
<td>.31</td>
<td>-.08</td>
</tr>
<tr>
<td>Tension</td>
<td>.04</td>
<td>.17</td>
<td>.04</td>
</tr>
<tr>
<td>Worrying</td>
<td>.38</td>
<td>.15</td>
<td>.40*</td>
</tr>
</tbody>
</table>

\( R^2 = .157, N = 59, *p \leq .05, \)

The same analysis was then replicated according to the service user’s legal status at admission. In caregivers of involuntarily admitted service users, levels of caregiving and burden accounted for 24% of the variability in scores of psychological distress, \( f(4, 37) = 2.90, p \leq .05 \). Burden acted as a significant predictor of psychological distress in caregivers of service users who were involuntarily admitted. However, no sub-section of the IEQ alone acted as a predictor in this model.
Table 9
Multiple Regression Scores for the Involvement Evaluation Questionnaire & General Health Questionnaire-12: Caregivers of involuntarily admitted service users

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>11.52</td>
<td>1.10</td>
<td></td>
</tr>
<tr>
<td>Urging</td>
<td>-.15</td>
<td>.16</td>
<td>-.16</td>
</tr>
<tr>
<td>Supervision</td>
<td>1.04</td>
<td>.52</td>
<td>.35</td>
</tr>
<tr>
<td>Tension</td>
<td>-.00</td>
<td>.22</td>
<td>-.00</td>
</tr>
<tr>
<td>Worrying</td>
<td>.30</td>
<td>.19</td>
<td>.30</td>
</tr>
</tbody>
</table>

R² = .24, N= 41, *p ≤ .05

In caregivers of service users who were voluntarily admitted, levels of caregiving and burden accounted for 60% of the variability in scores of psychological distress, f (4, 11) = 4.16, p ≤ .05. Burden acted as a significant predictor of psychological distress in this sample of caregivers. The model revealed that worrying was a statistically significant predictor of psychological distress (β = .78, p ≤ .05). An increase in worrying was linked to an increase in psychological distress in caregivers of voluntarily admitted service users.

Table 10
Multiple Regression Scores for the Involvement Evaluation Questionnaire & General Health Questionnaire-12: Caregivers of voluntarily admitted service users

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>7.43</td>
<td>1.15</td>
<td></td>
</tr>
<tr>
<td>Urging</td>
<td>.14</td>
<td>.11</td>
<td>.26</td>
</tr>
<tr>
<td>Supervision</td>
<td>-.39</td>
<td>.31</td>
<td>-.31</td>
</tr>
<tr>
<td>Tension</td>
<td>-.08</td>
<td>.20</td>
<td>-1.11</td>
</tr>
<tr>
<td>Worrying</td>
<td>.60</td>
<td>.19</td>
<td>.78*</td>
</tr>
</tbody>
</table>

R² = .60, N= 15, *p ≤ .05

A multiple regression was used to assess whether burden predicted expressed emotion in caregivers. A total Level of Expressed Emotion (LEE) score was entered as the dependent variable and the four Involvement Evaluation Questionnaire (IEQ) sub-scores were entered as predictor variables. IEQ scores did not predict total LEE score, f (4, 44) = 1.67, p > .05, R² = .13. When caregivers were divided according to the service user’s legal status at admission, IEQ scores failed to predict expressed emotion scores in caregivers of those admitted involuntarily, f (4, 29) = .76, p > .05, R² = .10. IEQ scores, however, predicted expressed emotion scores in caregivers of those voluntarily admitted,
f (4, 9) = 5.80, p .01. Burden accounted for 72% of the variability of scores of expressed emotion in caregivers of voluntarily admitted service users. An increase in urging was associated with an increase in expressed emotion scores (β = .93, p < .01).

**Table 11**

*Multiple regression scores for Level of Expressed Emotion sub-scales and burden in caregivers of voluntarily admitted service users.*

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>B</th>
<th>S.E.</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>4.29</td>
<td>1.87</td>
<td></td>
</tr>
<tr>
<td>Urging</td>
<td>.97</td>
<td>.23</td>
<td>.93*</td>
</tr>
<tr>
<td>Supervision</td>
<td>-.35</td>
<td>.65</td>
<td>-.16</td>
</tr>
<tr>
<td>Tension</td>
<td>.04</td>
<td>.51</td>
<td>.02</td>
</tr>
<tr>
<td>Worrying</td>
<td>-.21</td>
<td>.37</td>
<td>-.14</td>
</tr>
</tbody>
</table>

R² = .72, N = 15, *p ≤ .01

Simple regressions were used to determine whether caregiver burden was associated with any coping style in caregivers. All scores are reported in Table 12 below. Three coping styles emerged: denial, behavioural disengagement and religion. Denial represented 13% of the variability of scores of burden, [f (1, 52) = 7.46 p ≤ .01, R² = .13]. An increase in denial was associated with an increase in caregiver burden (β = .35, p < .01). Behavioural disengagement also represented 13% of the variability of scores for caregiver burden, [f (1, 52) = 7.46, p ≤ .01, R² = .13]. An increase in behavioural disengagement was associated with an increase in caregiver burden (β = .35, p < .01). Finally, religiosity represented 17% of the variability of burden scores, [f (1, 52) = 10.58, p ≤ .01, R² = .17]. An increase in religiosity was linked to an increase in burden scores for caregivers overall (β = .41, p < .01). However, when a Bonferroni correction was applied, no coping style was significant.

**Table 12**

*Simple Regression Scores for Denial, Behavioural Disengagement, Religion & Burden*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td>9.12</td>
<td>3.34</td>
<td>.35*</td>
</tr>
<tr>
<td>B. Disengagement</td>
<td>13.68</td>
<td>5.01</td>
<td>.35*</td>
</tr>
<tr>
<td>Religion</td>
<td>1.86</td>
<td>.57</td>
<td>.41*</td>
</tr>
</tbody>
</table>

*p ≤ .01
**Table 13**

*Simple Regression Scores for Coping Style & Burden in caregivers*

<table>
<thead>
<tr>
<th>Coping Style</th>
<th>Total</th>
<th>Involuntary</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>f</td>
<td>R²</td>
<td>F</td>
</tr>
<tr>
<td>Self distraction</td>
<td>.80</td>
<td>.02</td>
<td>.81</td>
</tr>
<tr>
<td>Active Coping</td>
<td>.19</td>
<td>.00</td>
<td>4.91*</td>
</tr>
<tr>
<td>Denial</td>
<td>7.46**</td>
<td>.13</td>
<td></td>
</tr>
<tr>
<td>Substance Use</td>
<td>1.20</td>
<td>.02</td>
<td>1.27</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>.52</td>
<td>.01</td>
<td>.43</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>.10</td>
<td>.00</td>
<td>2.28</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>7.46**</td>
<td>.13</td>
<td></td>
</tr>
<tr>
<td>Venting</td>
<td>1.45</td>
<td>.03</td>
<td>.78</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>2.25</td>
<td>.04</td>
<td>8.51**</td>
</tr>
<tr>
<td>Planning</td>
<td>1.31</td>
<td>.03</td>
<td>12.01**</td>
</tr>
<tr>
<td>Humor</td>
<td>2.49</td>
<td>.05</td>
<td>1.79</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.68</td>
<td>.01</td>
<td>.70</td>
</tr>
<tr>
<td>Religion</td>
<td>10.58**</td>
<td>.17</td>
<td>1.79</td>
</tr>
<tr>
<td>Self-blame</td>
<td>1.51</td>
<td>.03</td>
<td>.31</td>
</tr>
</tbody>
</table>

df = (1, 52) for Total; df = (1, 36) for Involuntary; df = (1, 13) for Voluntary

*p ≤ .05, **p ≤ .01
2. Subsidiary Hypothesis Two: That coping strategies would be linked to psychological distress and expressed emotion.

Simple regressions were used to observe whether coping style predicted psychological distress in caregivers. Venting was found to predict psychological distress in caregivers overall, \( f(1, 52) = 5.60, p < .05 \). Scores of venting accounted for 10% of the variability of scores of psychological distress. An increase in venting was linked to an increase in the level of psychological distress (\( \beta = .31, p < .05 \)). When a Bonferroni correction was applied, this finding was no longer significant.

**Table 14**  
*Simple Regression Scores for Venting and Psychological Distress*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>10.02</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Venting</td>
<td>.67</td>
<td>.28</td>
<td>.31*</td>
</tr>
</tbody>
</table>

\( R^2 = .10, \ N=53, *p \leq .05 \)

Simple regressions were also used to analyse whether coping style predicted caregivers’ levels of expressed emotion. Prior to dividing caregivers according to their relative’s legal status, one coping style was found to predict expressed emotion. Instrumental support accounted for 10% of the variability of scores of expressed emotion, \( f(1, 53) = 5.43, p \leq .05 \). A decrease in instrumental support is linked to an increase in expressed emotion (\( \beta = -.32, p < .05 \)). However, when a Bonferroni correction was applied, this finding was no longer significant.

**Table 15**  
*Simple Regression Scores for Instrumental Support & Expressed Emotion*

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE B</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>10.99</td>
<td>1.61</td>
<td></td>
</tr>
<tr>
<td>I. Support</td>
<td>-.66</td>
<td>.28</td>
<td>-.32*</td>
</tr>
</tbody>
</table>

\( R^2 = .10, \ N=54, *p \leq .05 \)
Table 16
Simple Regression Scores for Coping Style & Psychological Distress in caregivers

<table>
<thead>
<tr>
<th>Coping Style</th>
<th>Total</th>
<th></th>
<th>Involuntary</th>
<th></th>
<th>Voluntary</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>f</td>
<td>R²</td>
<td>f</td>
<td>R²</td>
<td>f</td>
<td>R²</td>
</tr>
<tr>
<td>Self distraction</td>
<td>1.58</td>
<td>.03</td>
<td>.34</td>
<td>.01</td>
<td>.97</td>
<td>.08</td>
</tr>
<tr>
<td>Active Coping</td>
<td>.42</td>
<td>.01</td>
<td>2.45</td>
<td>.06</td>
<td>2.44</td>
<td>.17</td>
</tr>
<tr>
<td>Denial</td>
<td>.06</td>
<td>.00</td>
<td></td>
<td>.44</td>
<td></td>
<td>.04</td>
</tr>
<tr>
<td>Substance Use</td>
<td>.28</td>
<td>.01</td>
<td>.98</td>
<td>.03</td>
<td>.58</td>
<td>.05</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>1.51</td>
<td>.03</td>
<td>.29</td>
<td>.01</td>
<td>.82</td>
<td>.06</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>3.13</td>
<td>.06</td>
<td>2.69</td>
<td>.07</td>
<td>.05</td>
<td>.00</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>.32</td>
<td>.01</td>
<td>.40</td>
<td>.01</td>
<td>.44</td>
<td>.04</td>
</tr>
<tr>
<td>Venting</td>
<td>5.60*</td>
<td>1.00</td>
<td>3.53</td>
<td>.09</td>
<td>1.39</td>
<td>.10</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>.74</td>
<td>.01</td>
<td>4.34*</td>
<td>.11</td>
<td>2.88</td>
<td>.19</td>
</tr>
<tr>
<td>Planning</td>
<td>.08</td>
<td>.00</td>
<td>.73</td>
<td>.02</td>
<td>1.01</td>
<td>.08</td>
</tr>
<tr>
<td>Humor</td>
<td>.63</td>
<td>.01</td>
<td>.41</td>
<td>.01</td>
<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.21</td>
<td>.00</td>
<td>1.39</td>
<td>.04</td>
<td>3.13</td>
<td>.14</td>
</tr>
<tr>
<td>Religion</td>
<td>.25</td>
<td>.01</td>
<td>1.5</td>
<td>.01</td>
<td>5.34*</td>
<td>.31</td>
</tr>
<tr>
<td>Self-blame</td>
<td>2.94</td>
<td>.05</td>
<td>.57</td>
<td>.02</td>
<td>6.06*</td>
<td>.34</td>
</tr>
</tbody>
</table>

df = (1, 53) for Total; df = (1, 33) for Involuntary; df = (1, 14) for Voluntary
*p ≤ .05; **p ≤ .01
<table>
<thead>
<tr>
<th>Coping Style</th>
<th>Total</th>
<th></th>
<th>Involuntary</th>
<th></th>
<th>Voluntary</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>f</td>
<td>$R^2$</td>
<td>f</td>
<td>$R^2$</td>
<td>f</td>
<td>$R^2$</td>
</tr>
<tr>
<td>Self distraction</td>
<td>.12</td>
<td>.00</td>
<td>.06</td>
<td>.00</td>
<td>1.22</td>
<td>.08</td>
</tr>
<tr>
<td>Active Coping</td>
<td>.00</td>
<td>.00</td>
<td>.20</td>
<td>.01</td>
<td>.37</td>
<td>.03</td>
</tr>
<tr>
<td>Denial</td>
<td>.44</td>
<td>.01</td>
<td></td>
<td></td>
<td>.44</td>
<td>.03</td>
</tr>
<tr>
<td>Substance Use</td>
<td>.62</td>
<td>.01</td>
<td>.26</td>
<td>.01</td>
<td>.54</td>
<td>.04</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>3.56</td>
<td>.07</td>
<td>8.22**</td>
<td>.20</td>
<td>.05</td>
<td>.00</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>5.43*</td>
<td>.10</td>
<td>4.26*</td>
<td>.11</td>
<td>1.07</td>
<td>.07</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>.11</td>
<td>.00</td>
<td>.47</td>
<td>.01</td>
<td>.44</td>
<td>.03</td>
</tr>
<tr>
<td>Venting</td>
<td>2.28</td>
<td>.05</td>
<td>2.06</td>
<td>.06</td>
<td>.37</td>
<td>.03</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>2.56</td>
<td>.05</td>
<td>1.81</td>
<td>.05</td>
<td>.83</td>
<td>.06</td>
</tr>
<tr>
<td>Planning</td>
<td>.21</td>
<td>.00</td>
<td>.64</td>
<td>.02</td>
<td>.07</td>
<td>.01</td>
</tr>
<tr>
<td>Humor</td>
<td>2.11</td>
<td>.04</td>
<td>3.61</td>
<td>.10</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.02</td>
<td>.00</td>
<td>.02</td>
<td>.00</td>
<td>.02</td>
<td>.00</td>
</tr>
<tr>
<td>Religion</td>
<td>.75</td>
<td>.02</td>
<td>.72</td>
<td>.02</td>
<td>7.51*</td>
<td>.35</td>
</tr>
<tr>
<td>Self-blame</td>
<td>2.32</td>
<td>.05</td>
<td>.48</td>
<td>.01</td>
<td>3.09</td>
<td>.18</td>
</tr>
</tbody>
</table>

*df = (1, 53) for Total; df = (1, 33) for Involuntary; df = (1, 14) for Voluntary*

*p ≤ .05; **p ≤ .01
3. Subsidiary Hypothesis Three: That social problem solving ability would be higher in the caregivers of those who were voluntarily admitted and that, as a coping strategy, social problem-solving would be linked to burden, psychological distress and expressed emotion.

This hypothesis was included as problem-solving is viewed as a coping strategy. The social problem-solving inventory is divided into five sub-scales: positive problem orientation (PPO), negative problem orientation (NPO), rational problem solving (RPS), impulsivity/carelessness style (ICS) and avoidance style (AS). Three of the five sub-scales: positive problem solving, rational problem solving and impulsivity/carelessness were normally distributed. The mean score of positive problem solving was 10.47 (SD ± 4.50). The median score for negative problem solving was 3 (interquartile range = 2, 7). The mean scores for rational problem solving and impulsivity/carelessness were 10.74 (SD ± 4.91) and 5.21 (SD ± 4.25) respectively. Finally, the median score of avoidance style was 3 (interquartile range = 1, 6). An independent t-test was performed to search for differences in problem-solving between caregivers of involuntarily or voluntarily admitted service users on positive problem orientation, rational problem solving and impulsivity/carelessness style. No significant difference was found between caregivers according to their broad legal status on positive problem solving \[ t (41) = -1.18, p > .05 \] , impulsivity/carelessness \[ t (41) = .92, p > .05 \] and rational problem solving \[ t (41) = -2.13, p \leq .05 \] . A Mann-Whitney U test was conducted to test whether negative problem solving and avoidance style scores differed according to legal status. Caregivers differed in negative problem orientation \( (U = 111, p \leq .05, r = .09) \) but not in avoidance style \( (U = 179, p > .05) \).

<table>
<thead>
<tr>
<th>Measure (M ± SD) / Median (IQR)</th>
<th>Total</th>
<th>Involuntary</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPO 10.47 ± 4.50</td>
<td>9.93 ± 4.56</td>
<td>11.69 ± 4.27</td>
<td></td>
</tr>
<tr>
<td>NPO 3 (2-7)</td>
<td>4 (3-10)</td>
<td>2 (0-6)</td>
<td></td>
</tr>
<tr>
<td>RPO 10.74 ± 4.91</td>
<td>9.73 ± 5.01</td>
<td>13.08 ± 3.93</td>
<td></td>
</tr>
<tr>
<td>ICS 5.21 ± 4.25</td>
<td>5.60 ± 4.64</td>
<td>4.31 ± 3.15</td>
<td></td>
</tr>
<tr>
<td>AS 3 (1-6)</td>
<td>3 (1-6)</td>
<td>4 (1-6)</td>
<td></td>
</tr>
</tbody>
</table>
Finally, a series of correlations were carried out to ascertain whether a relationship existed between social problem solving, caregiver burden and psychological distress. No associations were found between burden and positive problem orientation ($r = -.03, n = 42, p > .05$), negative problem orientation ($r = .18, n = 41, p > .05$), rational problem solving ($r = -.20, n = 42, p > .05$), impulsivity/carelessness ($r = .09, n = 42, p > .05$) and avoidance style ($r = .02, n = 40, p > .05$). Again, we found no significant association between psychological distress and positive problem orientation ($r = .09, n = 42, p > .05$), negative problem orientation ($r = .12, n = 41, p > .05$), rational problem solving ($r = -.12, n = 42, p > .05$), impulsivity/carelessness ($r = .06, n = 42, p > .05$) and avoidance style ($r = .14, n = 40, p > .05$).

Correlations were also used to examine whether a relationship existed between caregivers’ problem solving and expressed emotion. A series of correlations were carried out to test whether problem solving was associated with expressed emotion. We found no significant association between expressed emotion and positive problem orientation ($r = -.04, n = 42, p > .05$), negative problem orientation ($r = .15, n = 41, p > .05$), rational problem solving ($r = .11, n = 42, p > .05$), impulsivity/carelessness ($r = .25, n = 42, p > .05$) and avoidance style ($r = .15, n = 40, p > .05$).

This chapter outlined how the data were initially treated and analysed according to each hypothesis. The next chapter will summarise our key and subsidiary findings and outline whether these were supported or not. It will then compare our findings to the greater literature and highlight the implications of our findings within both a theoretical and clinical context. Lastly, it will emphasize the strengths and weaknesses of the study and suggest areas of improvement for future investigation.
Chapter Five

Discussion

This chapter will, firstly, summarise the findings of each hypothesis and describe how these relate to current and previous research. The focal point of this discussion pertains to our key hypotheses. However, both key and subsidiary hypotheses will be discussed. Secondly, it will aim to highlight the clinical and theoretical implications of our findings. Finally, it will examine the strengths and weaknesses of this quantitative study and provide suggestions on how to improve our understanding of caregivers’ and service users’ experiences through research.

5.1 Summary of findings

Key Hypotheses

1. Hypothesis One: That caregivers would perceive the admission as less coercive, less pressured and more procedurally just than service users, reflective of a second-hand experience.

Our first hypothesis was partly supported. Our sample of caregivers perceived the service user’s admission as less coercive than reported by service users. However, they did not significantly differ on scores of perceived pressures. Finally, caregivers perceived the service user’s admission as more procedurally just than service users.

Our findings support the only other study to directly compare caregivers’ and service users’ perspectives of coercion (Hoge et al., 1998). In Hoge et al.’s (1998) study, caregivers viewed
the admission as a more positive experience than reported by service users. Similarly to our findings, differences in levels of perceived coercion were only observed between those involuntarily admitted and their caregivers. Additionally, caregivers in both Hoge et al.’s and our study did not report differences in perceived pressures and perceived the admission as more procedurally just.

Although our findings support the only other study to directly examine caregivers’ and service users’ perceptions of the admission, differences in perspectives between caregivers and service users have also been reported in earlier research. Caregivers and service users tend to disagree on the number of needs they have (Foldemo, Ek, & Bogren, 2004), the type of needs (Cleary et al., 2006) and the type of supportive treatment they would like (Noble, 2004). Our study is, therefore, not alone in finding different perspectives between the two groups. Lower scores of perceived coercion in caregivers may be explained by caregivers’ higher scores of procedural justice. Although many of those involuntarily admitted perceive their admission as necessary (O'Donoghue et al., 2010), it is possible that caregivers’ scores of perceived coercion were affected by how procedurally just caregivers felt the admission was. It is possible that caregivers’ perceptions of procedural justice from the admission may be linked to their perceptions regarding the necessity of the admission.

The disparity in scores may also have been influenced by differences in the timing of the interviews as changes in perceptions may happen over time (O'Donoghue et al., 2011). Service users were interviewed during their hospitalisation and did not have the same amount of time to reflect on the admission as their caregivers. Some of the service users’ responses may have also been affected by poor insight at the time of interview (Amador, Strauss, Yale, & Gorman, 1991; McEvoy et al., 1989). Although it is likely that caregivers and service users’ have influenced each others’ views on the admission, the difference in their perceptions may be accounted for by their differences in experience. Whilst caregivers may have found the experience of admission distressing, their perceptions of the admission were based on a secondary rather than primary experience. Furthermore, as caregivers were interviewed more than a year after the service user’s discharge from hospital, it is possible
that caregivers drew upon previous experiences of admission in their accounts. Service users, however, were more likely to report their perceptions from the admission in question due to the timing of the interviews. Service user interviews occurred during hospitalisation and, depending on how close the interview was to the admission, at a time when the service user may still have been acutely unwell. It is possible that some service user may have had difficulties with insight depending on the diagnosis that may have affected how they perceived the admission. It is, however, also possible that caregivers’ scores were impacted by memory recall and that, after time, service users and caregivers may have shared and influenced each others’ perceptions regarding the admission.

This finding may have important theoretical and clinical implications. This disparity in perceptions regarding the admission may highlight that caregivers find the admission less negatively impacting than service users who may be more reluctant to be re-admitted. It may also emphasise that there are gaps in communication between caregivers and service users. Engaging caregivers in their relative’s care to a greater extent and allowing both caregivers and service users to have a platform for sharing their experiences prior to the service user's discharge from hospital may help improve communication and reduce this disparity of views. Such a platform could allow service users to identify their preferences for future treatment and formulate advance directives that are understood and acknowledged by both caregivers and service providers to help service users feel some control over their treatment and, therefore, to prevent them from perceiving future admissions as coerced or against their wishes (Khazaal et al., 2014).

2. Hypothesis Two: That caregivers of involuntarily admitted service users would reveal higher levels of perceived coercion and perceived pressures and lower levels of procedural justice than caregivers of voluntarily admitted service users.

Our second hypothesis was not supported. In this sample, it was the caregivers of those who were voluntarily admitted who perceived their relative’s admission as more coerced than
caregivers of those admitted involuntarily. Caregivers of involuntarily and voluntarily admitted service users also differed in the perceptions of pressures of their relative’s admission with service users perceiving the admission as more coerced. However, we were unable to isolate this difference according to specific legal status (ie whether they were admitted involuntarily, initially admitted voluntarily and subsequently detained or admitted voluntarily). Finally, caregivers of involuntarily admitted service users perceived their relative’s admission as more procedurally just that caregivers of those voluntarily admitted.

As this is the first study evaluating caregivers’ perceptions of coercion, pressures and procedural justice according to their relative’s legal status, we do not have other research to compare it to. Nevertheless, these perceptions have been traditionally measured according to legal status in service users. In service users, elevated perceptions of coercion and perceived pressures tend to be linked to an involuntary legal status (Lidz et al., 1998). Perhaps surprising is our finding that caregivers whose relative was admitted voluntarily perceived the admission as more coercive, suggesting that caregivers and service users are drawing on different aspects of the experience. In a study by Ostman and Hansson (1999) examining the perceived necessity of support and involvement of caregivers of involuntarily and voluntarily admitted service users, caregivers of those who were voluntarily admitted reported a greater level of involvement in the service user’s care. We, therefore, posit that it may be this increased perception of involvement in the service user’s care that leads caregivers to perceive the service user’s admission as more coercive.

This finding has important implications for clinical practice. Contrary to Ostman and Hansson’s (1999) conclusions that services need to provide more attention to the relatives of those who are involuntarily admitted, we suggest that the caregivers of those voluntarily admitted require an equal amount of support. Furthermore, we hypothesise that lower perceptions of coercion in caregivers of those who were involuntarily admitted may be linked to being supported by the mental health services who recognize the need for admission. Those caregivers whose relative was admitted voluntarily may feel overlooked by the mental health services who do not perceive a need for providing immediate medical attention to the
service user and, therefore, may experience guilt upon admission. Therefore, it is important that the caregivers of those who are voluntarily admitted are not overlooked by the mental health services and that suitable support is provided to them.

3. **Hypothesis Three: That caregivers of involuntarily admitted service users would feel more burdened and psychologically distressed than caregivers of voluntarily admitted service users.**

Our third hypothesis was partly supported. We did not find a significant difference in levels of overall burden between caregivers of those admitted involuntarily and voluntarily. However, when our data were analysed according to each individual aspect of burden, we found a significant difference in the level of supervision displayed by caregivers according to legal status. Caregivers of voluntarily admitted service users supervised their relatives to a greater extent than caregivers of involuntarily admitted service users. No other dimension of burden appeared to be linked to legal status. Furthermore, caregivers of involuntarily admitted relatives did not appear to significantly differ from caregivers of those voluntarily admitted in their levels of psychological distress in this study.

To our knowledge, no previous study to date has examined whether differences in the service users’ legal status at admission accounted for differences in caregiver burden (objective and subjective) at more than one-year follow-up. Our findings, however, support those of Boydell et al. (2014), who also emphasized that burden overall was not linked to involuntary admission in caregivers of first episode psychosis (Boydell et al., 2014). Our scores of burden and psychological distress are substantially lower than those reported by other authors (van Wijngaarden et al., 2000). Thus, the similarity in scores between caregivers in this sample may be due to a reduction in overall caregiver burden following the service user’s hospitalisation or due to time regardless of legal status (Heru, 2004).
One dimension of burden, supervision, was associated with service users’ voluntary legal status. This finding may be linked to a number of reasons. It may be indicative of a continued expression of concern, and therefore, a need for mental health services to reassure caregivers and share responsibility for providing ongoing care. It may, however, also imply a need for caregiver support and psychoeducation that provides caregivers with a toolkit of coping strategies. This may be linked to a lower level of perceived social support from family and mental health professionals (Moller-Leimkuhler & Wiesheu, 2012; Song, Biegel, & Milligan, 1997) and, in turn, a poorer sense of mastery and personal control over the service user’s illness (Reinhard, 1994). Finally, it may indicate a continued or elevated level of illness in voluntarily admitted service users that necessitates supervision after discharge.

4. **Hypothesis Four:** That caregivers of involuntarily admitted service users would project higher levels of expressed emotion than caregivers of voluntarily admitted service users.

Our fourth hypothesis was partly supported. We found no significant difference in expressed emotion overall between caregivers of involuntarily and voluntarily admitted service users. Although most caregivers reported low levels of expressed emotion, when each aspect of the Levels of Expressed Emotion scale was analysed, we found a significant difference in the emotional response displayed by the caregivers of involuntarily and voluntarily admitted service users. Our findings, however, may suggest that caregivers whose relative was involuntarily admitted tended to display higher levels of negative emotional response towards their relative. No other dimension of expressed emotion was found to differ according to the service user’s legal status. However, one must be cautious in interpreting these results due to our small sample size.

Expressed emotion has not been previously assessed according to the service user’s legal status and, therefore, we are unable to produce a comparison. However, as expressed emotion is linked to caregiver burden in earlier studies, we postulate that the low rate of expressed
emotion overall reported by caregivers may be linked to a low level of caregiver burden exhibited following the service user’s hospitalisation. As documented in earlier studies that noted changes in levels of expressed emotion for a quarter to a third of families, it is possible that reports of expressed emotion may have lessened once the service user received treatment (Patterson et al., 2005; Scazufca & Kuipers, 1998). As expressed emotion has been notably linked to relapse in the literature (Bebbington & Kuipers, 1994; Scazufca et al., 2001; Simmons et al., 2008; Weigel et al., 2006), our finding that caregivers of involuntarily admitted service users expressed more negative emotional response may help us identify those service users most at risk of relapse. However, this finding should be taken with caution for two reasons. Firstly, the studies that previously found a predictive relationship between expressed emotion and relapse used a different assessment of expressed emotion. Additionally, we are missing a more recent meta-analysis examining whether these two factors are realistically linked. Nevertheless, our finding may imply that there continues to be a need for family intervention programmes in caregivers that include psycho-education and relapse prevention through target expressed emotion reduction (Dennis & Leach, 2007; Hashemi & Cochrane, 1999).

5. **Hypothesis Five: That caregivers of involuntarily admitted service users would adopt more emotion-focused than problem-focused coping strategies than caregivers of voluntarily admitted service users.**

Our fifth hypothesis was not supported. We did not observe any significant differences between the coping styles adopted by caregivers that depended on service users’ legal status. This is the first study evaluating coping styles according to the service user’s legal status and therefore we do not have earlier studies to compare our findings to. Nevertheless, poorer coping mechanisms have been associated with higher levels of burden within the literature (Magliano, Fadden, Economou, et al., 1998; Scazufca & Kuipers, 1999). Avoidant coping styles have been linked to caregivers with high levels of burden, psychological distress and to those who report high levels of expressed emotion (Cotton et al., 2013; Goossens et al., 2008; Hinrichsen & Lieberman, 1999; Onwumere et al., 2011; Scazufca & Kuipers, 1999; Smith et
al., 1993). As caregivers in this study displayed lower levels of all these factors, we propose that they may have been less likely to require coping and, therefore, less likely to draw upon a particular coping style at the time of interview. It is important for future research to assess whether coping styles may differ according to legal status if evaluated closer to the service user’s admission.

6. **Hypothesis Six:** That caregivers’ appraisal of the admission (perceived coercion, pressures & procedural justice) would be linked to caregiver burden and psychological distress, irrespective of legal status.

Our final key hypothesis was partly supported. Neither perceived coercion or perceived pressures were linked to scores of caregiver burden nor distress. The third dimension of the MacArthur Admission Experience Survey, procedural justice, appeared to be significantly associated with burden and psychological distress. An increase in scores of procedural justice was associated with a decrease in levels of burden and distress. When analysed according to legal status, procedural justice was linked to burden in caregivers of involuntarily admitted service users but not in caregivers of voluntarily admitted service users. However, this relationship was not noted for psychological distress. These significant findings relating to procedural justice are particularly interesting given that caregivers of involuntarily admitted service users perceived higher levels of procedural justice than caregivers of voluntarily admitted service users; a finding that was opposite to that found in the service users themselves. This finding may indicate that this group of caregivers may perceive immediate involuntary admission as critical to their and/or the service user’s health and may therefore, in this light, justify the manner in which their relative was admitted.

There is a dearth of research exploring caregiver burden and psychological distress in the context of the caregiver’s perspective of the admission. To our knowledge this is the first study to explore caregivers’ perceptions of coercion, pressures and procedural justice and therefore is the first to indicate a relationship between burden and psychological distress and caregivers’ perceptions of procedural justice. Our findings suggest that caregivers who
perceive the service user’s admission as procedurally just are less likely to suffer from burden or psychological distress. This may imply that caregivers who perceive their relative’s admission as occurring out of concern, fairly and respectfully, reflectively feel at ease with the admission itself. On the other hand, those who perceived that their relative was treated unfairly and was disrespected when entering hospital involuntarily may feel more burdened from and responsible for the admission. Alternatively, those who feel less distressed or burdened may view hospital admission in a more positive light. Primary appraisals of psychiatric admission have been previously linked to psychological distress and burden in caregivers (Barrowclough & Parle, 1997; Fortune et al., 2005; Moller-Leimkuhler, 2005; Provencher et al., 2000). Using the lens of the stress and coping theoretical model, it is likely that caregivers, in time, re-appraised their relative’s admission, their contextual experiences and their coping abilities and found their coping reserves to match the perceived difficulty of the admission resulting in lower levels of burden and psychological distress. This finding may also suggest that services might benefit from assessing caregivers’ perceptions regarding the admission in an effort to screen for burden and reduce the possibility of negative outcomes.

Subsidiary Hypotheses


The first of our subsidiary hypotheses was supported. Worrying, as one of the main dimensions of burden, significantly predicted psychological distress in our sample of caregivers. An increase in levels of worrying was associated with an increase in psychological distress. This finding is not novel, rather, it confirms what is already available in the literature. For example, although few of the caregivers sampled in our study revealed higher levels of burden, our findings provide some support to the idea that burden is linked to higher instances of mental health difficulties in caregivers (Perlick et al., 2007). Our finding sustains van Wijngaarden and colleagues’ model (as written in the Involvement Evaluation
Questionnaire) who viewed psychological distress as a form of subjective burden arising from providing unpaid care to an individual with a mental illness (van Wijngaarden et al., 2000). It is curious, however, that the remaining sub-scales of burden: urging, supervision and tension were not linked to psychological distress. This finding may be linked to lower levels of burden experienced by caregivers one year after the admission. The Involvement Evaluation Questionnaire particularly focuses on burden pertaining to helping with personal and physical activities, keeping the service user safe from harm and limitations on the caregiver’s life arising from the service user’s illness. Following the service user’s admission, it is possible that caregivers experience less psychological distress as a result of the service user accessing treatment and therefore requiring less aid with such activities that restricts the caregiver’s time.

2. **Subsidiary Hypothesis Two: That caregiver burden would predict expressed emotion, irrespective of legal status.**

Our second subsidiary hypothesis was not supported. Total burden scores were not linked to expressed emotion. This finding starkly contrasts research where these two constructs were associated (Moller-Leimkuhler, 2005; Scazufca & Kuipers, 1996; Smith et al., 1993). In previous studies, burden was perceived as likely to generate negative emotions. Higher levels of expressed emotion were found in those with higher levels of caregiver burden (Carra, Cazzullo, & Clerici, 2012; Scazufca & Kuipers, 1996; Smith et al., 1993). Our finding, however, is likely to be impacted by the timing of the caregiver interviews as both caregiver burden and expressed emotion appear to be lower than found in the normative scores reported in our third chapter.

According to Scazufca and Kuipers (1996), a decrease in burden only occurred when caregivers of individuals with schizophrenia switched from expressing a high level of emotion to a low level of emotion. Our findings may, therefore, indicate that a low level of overall burden is accompanied by a low level of overall expressed emotion in caregivers. From a clinical perspective, supportive caregiver programmes that aim to reduce high levels
of one of these constructs may, as a result, reduce the other and improve outcomes for both caregivers and service users.

3. **Subsidiary Hypothesis Three: That caregiver burden would predict the coping strategies used by caregivers, irrespective of legal status.**

Our third subsidiary hypothesis was not supported. Burden was initially predictive of three coping styles in particular: denial, religion and behavioural disengagement. An increase in denial and religiosity were associated with an increase in caregiver burden. Additionally, an increase in behavioural disengagement was associated with an increase in caregiver burden. However, when posthoc analyses were conducted, this finding was no longer statistically significant.

Our finding fails to support that of previous research that found poorer coping in caregivers who felt more burdened (Magliano, Fadden, Madianos, et al., 1998; Scazuftca & Kuipers, 1999). As the brief COPE was composed of fourteen different coping styles, our sample size significantly restricted the power of the analyses we conducted. Furthermore, the coping styles documented by caregivers may have been affected by the timing of the caregiver interviews. As interviews took place a minimum of a year after the admission, lower levels of burden and expressed emotion at that time may have been the result and also fed into a reduced need to adopt coping styles pertaining to the service user’s ill health.

4. **Subsidiary Hypothesis Four: That coping strategies would be linked to psychological distress.**

Our fourth subsidiary hypothesis was not supported. One coping strategy was initially linked to psychological distress: venting. An increase in venting was linked to an increase in the
level of psychological distress. However, upon conducting posthoc analyses, this finding was no longer significant.

The coping strategies employed by caregivers did not affect their levels of psychological distress. This finding is does not support the literature that emphasizes that unhelpful or dysfunctional coping mechanisms were also linked to negative appraisals of caregiving, higher levels of psychological distress and anxious and depressive symptoms (Jansen et al., 2015; Onwumere et al., 2011; Scazufca & Kuipers, 1999). In an earlier study by Fortune and colleagues, those who employed positive reframing as a coping mechanism reported lower levels of psychological distress and those who adopted self-blame revealed higher levels of psychological distress (Fortune et al., 2005). However, religion, active coping, seeking emotional support and acceptance were associated with lower levels of distress in their study and revealed no significant associations in ours (Fortune et al., 2005). Our results, therefore, do not support studies that suggest that emotion-focused coping strategies are significantly related to psychological distress (Grossi, 1999). Nonetheless, caregivers’ psychological distress may also be a by-product of overestimating their capacity to cope with their relative’s illness (Schulze-Monking, 2003, as cited in Moller-Leimkuhler, 2005). Our some of our previous findings indicated a need for mental health services to equip caregivers with a toolkit for adapting the coping styles they draw upon into more helpful forms to both caregivers and service users. Although this particular set of findings did not support previously published literature, a replication of the study powered by a greater sample size may give us more insight into caregivers’ coping strategies.

5. Subsidiary Hypothesis Five: That coping strategies would be linked to expressed emotion, irrespective of legal status.

Our fifth subsidiary hypothesis was supported by our data. Prior to dividing caregivers according to their relative’s legal status, one coping style, instrumental support, was found to predict expressed emotion. A decrease in instrumental support was linked to an increase in
expressed emotion. In caregivers of those who were involuntarily admitted, emotional support was found to predict expressed emotion. A decrease in emotional support was associated with an increase in expressed emotion. Instrumental support was also found to affect expressed emotion. Again, a decrease in instrumental support was associated with an increase in expressed emotion. In caregivers of those who were voluntarily admitted, religion was found to predict expressed emotion. Those who adopted religiosity as a coping style to a greater extent, revealed higher levels of expressed emotion.

Avoidant coping is a strong predictor of high expressed emotion in caregivers (Raune et al., 2004) and may also be a maintaining factor for expressed emotion (Barrowclough & Parle, 1997). According to Magliano et al. (1999), emotion-focused coping mechanisms were predominant in individuals who sustained enduring stress such as caregivers with high expressed emotion. Our findings, therefore, supported those of Magliano et al. (1999) as they indicated that expressed emotion was higher in those who did not seek emotional or instrumental support.

These findings indicate that a perceived lack of support in caregivers is linked to higher levels of expressed emotion. It also highlights that the caregivers of those who were voluntarily admitted with higher levels of expressed emotion, and as posited before, who continue to supervise their relative to a greater extent following discharge tend to draw upon unhelpful emotion-focused coping mechanisms. This is a strong indicator of a need for mental health services to examine the help they provide to caregivers of those who were voluntarily admitted a year after the service user’s admission. Providing a caregiver with the appropriate support at this time point may reduce the incidence of expressed emotion and, therefore, relapse.
6. Subsidiary Hypothesis Six: That caregivers of those admitted voluntarily would have higher levels of social problem solving as a form of coping and, in turn, that this would be linked to burden, psychological distress and expressed emotion.

Our final subsidiary hypothesis was not supported. We did not find a significant difference between caregivers on positive problem solving, impulsivity/carelessness, rational problem solving and avoidance style. Caregivers of involuntarily admitted service users, however, were flagged as employing higher levels of negative problem orientation. Finally, no associations were found between social problem solving and burden, psychological distress or expressed emotion.

Problem-solving is regarded as a form of coping (D'Zurilla & Chang, 1995). By problem-solving, an individual consciously attempts to reduce or ameliorate problems as a way of coping with them (Nezu, 2005). Our data initially indicated that caregivers of involuntarily admitted individuals revealed higher levels of negative problem orientation compared to their counterparts. This finding can be linked to the coping mechanisms displayed in the previous subsidiary hypotheses in caregivers of involuntarily admitted service users. This conclusion was similar to that of D'Zurilla and Chang (1995) who suggested that those with a higher level of negative problem orientation frequently adopted emotion-focused coping styles. However, due to the small sample sizes involved in this aspect of this analysis, it is likely that such a result may be due to a type II error and is therefore disqualified.

According to Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986), problem focused coping is adopted by individuals who perceive that the problematic situation they encounter is changeable. When individuals perceive that these problems will not change, they tend to employ emotion focused coping strategies. In accordance with our findings, caregivers of service users who were involuntarily admitted may perceive that their relative’s illness is enduring and unchangeable. They may also feel unable to generate solutions to a problem that is viewed as enduring (MacNair & Elliott, 1992). From our findings, we cannot state that emotion focused coping was employed by caregivers of voluntarily admitted service
users nor can we state that they found the difficulties surrounding their relative’s illness as more likely to change. Our finding also differs from other suggestions that individuals showing distressed or depressive symptoms suffered from a reduction in their ability to make effective decisions and appraisals of problem-solving (Nezu, 1986; Nezu & Nezu, 1987). Furthermore, according to Nezu and Ronan (1985), problem-focused coping is effective in buffering psychological distress arising from problematic situations.

5.2 Theoretical Model

Our findings point to a possible theoretical model of how caregivers’ observations or perceptions regarding the service user’s experienced admission may relate to psychological factors present in caregivers. In our literature review, we used the stress-coping paradigm to describe how caregivers’ perceptions of the admission, in the form of appraisals, may relate to conceptual factors (most notably burden and psychological distress) and, consequently, coping. However, here we will propose a slight variation on this theory according to the service user’s legal status at admission.

We postulate that legal status may be an important contributor to mental health caregivers’ stress and coping patterns. Here, we observed that the caregivers of those who were involuntarily admitted tended to appraise their relative’s admission in a more positive light, as shown by their lower levels of perceived coercion and higher scores of procedural justice, and that these higher scores of procedural justice were linked to lower levels of burden and psychological distress. This group of caregivers also tended to appraise their relative more negatively, as highlighted by higher scores on the negative emotional responses subscale, which was linked to lower levels of exhibited coping strategies such as acceptance, positive reframing and planning.

However, the caregivers of those who were voluntarily admitted held differing appraisals of the admission. These experienced their relative’s admission as more coerced and less procedurally just. These caregivers who viewed the admission more negatively tended to
have higher levels of burden, in the form of supervision, that were linked to displays of expressed emotion.

Unfortunately, not every aspect of the stress-coping theoretical framework proposed in this study was supported by our findings. We propose that this may, in part, be due to the timing of the interviews. Caregivers revealed lower levels of distress, burden and expressed emotion at the time of interview which may not have necessitated the coping styles found in other research. Furthermore, a replication of our proposed model with a larger sample of caregivers of service users admitted to hospital at the time of interview may reveal different insights into both the caregiving experience and psychological factors associated to the perception of the admission.

5.3 Strengths and Limitations

Our study contains a number of methodological strengths and weaknesses. An example of such strength pertains to our participant sampling. Our results were drawn from caregivers of both involuntarily and voluntarily admitted service users. This allowed us to make direct comparisons between caregivers according to the service user’s legal status at admission. Furthermore, caregivers were sampled from three mental health catchment areas that represented both urban and rural caregivers within Ireland. Participants stemmed from a randomized process of selection at admission rather than from self-selection, which increased the representativeness of our caregivers’ viewpoints. In addition, as reflected in other research, the caregivers who were sampled in this study were predominantly female and parents to the service user, therefore helping us compare our findings to that of other mental health caregiver studies. (Giacco et al., 2012; Magliano, Fadden, Madianos, et al., 1998; Winefield & Harvey, 1993).

A significant weakness of our study pertains to our first hypothesis. The timing of our comparisons between caregivers and service users on their perceptions of coercion, pressures and procedural justice significantly differed. Service users’ perceptions of their admission
were collected shortly after their admission. Caregivers’ perceptions, however, were obtained a minimum of a year after the service user’s discharge. This difference in timing inhibits us from drawing implications based on direct comparisons. Our study posed two principal limitations. Secondly, inviting caregivers to partake in the study one year after their relative’s discharge from hospital may have introduced a recall bias. As previous research has noted that service users’ perspectives of their admission may change over time, so may caregivers’ (O’Donoghue et al., 2010). The quantitative results presented within this thesis are the product of two combined studies examining the effects of the Mental Health Act 2001 on service users. The two studies were combined due to the similarity of their psychometric instruments and in an effort to increase the number of caregiver participants. Conversely, follow-up data was solely available from half of the service users interviewed at the time of writing. Thus, service users were interviewed during their hospitalisation and did not have the same amount of time to reflect on the admission as their caregivers. Although other studies have alluded to the plausible influence of treatment satisfaction following hospitalisation on accurate caregiver recall (Giacco et al., 2012), our findings were similar to those of Hoge et al. (1998) who interviewed both groups during hospitalisation. Secondly, our low consent rate for participation from service users may have introduced a selection bias within our sample. Although obtaining ethical consent from both parties is ethically sound, caregivers who were interviewed may have had better family relations with the service user (Giacco et al., 2012). This appears to be a frequent problem in family research in psychiatry and efforts have been made to include caregivers on the basis of their sole consent (Garety et al., 2008). Additionally, data regarding those who did not consent to participate or give consent for their caregiver to participate were unavailable and, therefore, we cannot draw comparisons based on their characteristics. However, a systematic review examining such characteristics could not decisively conclude that either age or disability were linked to health studies’ participation due to contradictory evidence (Kho, 2009). Regardless, our consent rate, however, is consistent with prior research (38-59%) (Giacco et al., 2012; Hoge et al., 1998). Therefore, it is possible that research to date involving caregivers could potentially under-estimate the disparity in perceptions on coercion. In order to gain a full
perspective on these important issues and involve all caregivers, it may be important to consider whether the consent process should focus solely on caregivers.

Thirdly, a significant limitation of our study pertains relates to the imbalanced representation of service users and caregivers according to legal status at admission. The majority of our sample consisted of service users and caregivers who were involuntarily admitted. A more balanced sample may provide more answers regarding the experiences of both parties. Furthermore, although challenging to sample due to a much smaller pool of potential participants, the experiences of those who were brought to hospital involuntarily but not voluntarily detained may shed some important information.

Finally, another limitation of our study pertains to our measure of caregiving and burden. Although the Involvement Evaluation Questionnaire is a well-validated measure of caregiving and caregiver burden, it solely assesses the negative factors related to caregiving. As previous research has ascertained that caregivers often perceive that their caregiving role also provides them positive experiences, including a measurement that assessed both the positive and negative experiences of caregiving may have been offered us a more balanced approach. On a final note, an increase in any of the constructs measured may be associated to factors that were not measured. For example, caregivers who were psychologically distressed at the time of interview may have experienced a low level of family functioning (Szmukler, Burgess, et al., 1996). Including such measures and carefully examining the impact of such factors on both service user consent for caregiver participation, willingness to participate in caregivers and caregiver responses during interview could provide us with important clues which in this study went unmeasured.

5.4 Directions for Future Research

Studies addressing the effects of caring for a relative with a mental illness have primarily examined the constructs of burden and expressed emotion. Recent studies have shifted from adopting the construct of burden as a universal indicator of caregiving and have begun to
address possible differences in caregiving across different diagnostic groups. However, caregiver research would extensively benefit from longitudinal studies that assessed plausible changes in caregivers’ perceptions across time. These should also aim to incorporate both the positive and negative aspects of caregiving. On a theoretical note, a replication of the study closer to the service user’s admission with a larger sample size may help reveal a clearer picture of how caregivers’ perceptions of coercion and, in particular, procedural justice interact with caregivers’ psychological factors. Such a study should aim to provide a powered analysis of caregivers’ experiences when experiencing high and low levels of burden and expressed emotion.

Examining the caregivers’ perception of coercion during their relative’s admission is a relatively novel idea. Our study is limited by the disparity in timing between the service user and caregiver interviews. Future studies could bridge this gap by collecting caregivers’ and service users’ views on perceived coercion, pressures and procedural justice at similar time points in the admission and at follow-up. These studies should include equal samples of caregivers of service users during their first episode of illness and those who have multiple experiences with in-patient mental health services and according to the service user’s legal status. Furthermore, assessing the extent to which caregivers are offered family interventions, carer-focused education and support programmes as recommended within the National Institute for health and Care Excellence (NICE) guidelines may reveal disparities across services that need to be addressed and may partly explain why caregivers continue to experience difficulties a year after the service user’s admission.
Part II:

Qualitative examination of caregivers’ perspective of the service user’s admission to an acute mental health unit

Chapter Six: Introduction
Chapter Seven: Methods
Chapter Eight: Results
Chapter Nine: Discussion
Chapter Six

Introduction

This chapter, firstly, presents our rationale for conducting this qualitative study of caregivers’ perceptions of their relative’s admission. It then briefly discusses some of the background literature applicable to this study and builds upon the concepts discussed in our literature review. We will then conclude by introducing the next chapter that describes how caregivers’ perspectives will be assessed and interpreted qualitatively.

This study partly emerged from an observed need to collect caregivers’ rich and personal experiences of caregiving during our quantitative study. Although our quantitative study highlighted the experiences of caregivers on measurable and well-established theoretical constructs pertaining to caregiving, it did not portray a full picture of caregivers’ experiences. As evidenced by previous research, a fuller picture may display caregivers’ array of feelings and motivations for the admission that are not always quantifiable but inform such constructs. This study, therefore, arose in response to observing such feelings and motivations during the quantitative study and perceiving a need for these to be expanded on and qualitatively reported within the future literature. Of particular emphasis within this study, are caregivers’ reports of both negative and positive factors associated with a caregiving role.

As mentioned in our first chapter, caregivers’ roles have shifted substantially since deinstitutionalisation. Historically, treatment relied heavily upon long periods of hospitalisation, however, caregivers are now increasingly providing care within the family home. Therefore, our next goal was to search for what is known about caregivers’ perceptions regarding the admission since deinstitutionalization within the context of a stress-coping model. Predominantly examining these qualitative experiences of admission and hospitalisation may help improve our understanding of the stress-coping model as applied to a psychiatric caregiver. In line with this model, caregivers’ appraisals regarding the service
user’s illness are linked to their emotional and behavioural responses (Treasure, 2003; Whitney et al., 2005). These appraisals are important as they influence both caregivers’ and service users’ outcomes (Scazuca & Kuipers, 1999).

Within the caregiver literature, a number of different appraisals appear. As highlighted in the literature review, one of the most established appraisals of caregiving pertains to burden – both objective and subjective. Objective burden is linked to appraising service users as less responsible for the negative symptoms, those found to be most challenging for caregivers, of their illness (Fadden, Bebbington, & Kuipers, 1987; Provencher & Mueser, 1997). The most frequently reported objective or situational difficulties that caregivers find burdening refer to restrictions in personal or leisurely activities, routine disruptions and family conflict (Reinhard, 1994). On the other hand, the most frequently distressing factors that contribute to caregivers’ subjective burden refer to worries regarding the future, feelings of loss and dealing with stigma (Reinhard, 1994).

In later research, subjective burden is related to feelings of shame and perceived stigma regarding the illness, guilt or responsibility for their relative’s illness and being unable to intervene sooner and worry for the service user’s wellbeing (Reinhard, 1994; Treasure et al., 2001; Whitney & Eisler, 2005). In addition to these feelings, some caregivers report feelings of resentment towards the service user and grieve the loss of the relationship they shared with their relative before the illness and dreams or hopes they may have had for their relative’s future (Parker, 1993; Reinhard, 1994). However, unlike other illnesses where individuals can experience loss after the death of a loved one, caregivers of individuals with an enduring and serious mental illness experience a recurring sense of grief where bouts of recovery may cause both joy and, in part, apprehension about the possibility of subsequent illness (Parker, 1993). Such negative appraisals accompanied with unmet needs in caregivers may impact caregivers’ levels of distress. For example, feelings of guilt and depression may linger when families do not receive needed reassurance (Lefley, 1987).
The following paragraph provides a prototype of how caregivers’ feel and reflect upon the service user’s admission and hospitalisation. Caregivers report feeling traumatised by their experiences of admission and hospitalization (Wheeler, 1994). Fear of violence, uncertainty and frustration regarding accessing suitable mental health treatment at a time when the service user is acutely unwell are commonplace within caregivers’ accounts. Once admission occurs, such fears are partially dissipated and replaced by relief upon acquiring help for the service user. In these instances, hospitalisation is regarded as a ‘safe environment’ and an opportunity for the service user to recover (Jansen et al., 2015). Hospitalisation, here, provides hope to families who yearn for an intervention that may alleviate the service user’s illness (Jansen et al., 2015). However, the result of hospitalization is not always viewed positively. Expressing frustration and anger with not being involved in their relative’s care despite being bestowed with their care upon discharge without consideration for their own wishes is not infrequent in families’ reports (Parker, 1993). This frustration is often centered on feeling excluded and, in some case, belittled by the mental health services who, according to caregivers, neglect their need for information and authority in providing care to their relative upon discharge (Biegel & Song, 1995; Jansen et al., 2015). Caregivers who, more recently, seek hospital treatment for their relative are met with shorter lengths of hospitalisation that, in some instances, lead to an untreated illness requiring further admissions (Biegel, 1998; Biegel & Schulz, 1999). Thus, this frustration is also the outcome of an observed lack of recovery that necessitated re-hospitalisation. Following the service user’s discharge under these circumstances, caregivers may develop a sense of powerlessness whereby they perceive that access to helpful treatment or appropriate mental health services is unattainable. This may invoke fear regarding the service user’s ability to cope with the illness within the community and their treatment during (subsequent) hospitalisation (Parker, 1993).

Although caregivers may express anger towards the mental health ‘system’, this anger may also sometimes be directed at other relatives who may hold different opinions of the illness and the best way to treat it and, temporarily, at the service user for having the illness (Parker, 1993). This anger may, in time, take different forms depending on the relationship shared
between the caregiver and the care recipient. For example, parents may feel anger for needing to re-assume a primary caregiving role whilst siblings may feel that the service user becomes the focal point of their parents’ attention (Parker, 1993).

As highlighted above, many of these appraisals are negative, linking caregiving to negative experiences such as feeling isolated, unsupported by mental health services and unable to obtain sufficient help or respite to facilitate their role (Biegel, 1998; Biegel & Song, 1995). Although caregiving is associated with burden and psychological distress as evidenced in earlier chapters, caregivers have also reported positive experiences. For example, the adult children of individuals with a serious mental illness refer to caregiving as a way of paying their parent back for the care they received as a child (Beach, Schulz, Yee, & Jackson, 2000). Furthermore, caregivers have cited their adaptation to caregiving as a process of personal growth and learning both about mental illness and family dynamics (Bulger, Wandersman, & Goldman, 1993). Caregivers have noted that their role is facilitated by positive attitudes and appraisals (Doornbos, 1997). Those who were tolerant, patient and loving with their relative, who were forgiving of their perceived mistakes and encouraged their relative to re-engage, found their role less burdening and reported being less affected by the unpredictable enduring nature of the service user’s illness.

In turn, as highlighted in the literature review, caregivers’ appraisals may shape their ability to cope with their role (Biegel, 1998; Biegel & Song, 1995). Although all the studies enlisted above help us piece together a puzzle of how caregivers may experience their relative’s admission across different countries and decades, we do not presently hold a current construct of caregivers’ perspectives that incorporate both positive and negative experiences across countries. Many of the studies evidenced above were older, not always consolidated by more recent research and short-sampled.

The present study will collect the experiences of caregivers of involuntarily admitted service users only. Although earlier research presented within our first chapter showed that involuntarily and voluntarily admitted service users perceived their admission as coercive to a
certain degree, it also highlighted a distinct correlation between these perceptions and the experiences of those who were involuntarily admitted (Hoge et al., 1997; Kjellin, 1999; Monahan et al., 1995). In line with this research and with the suggestion that caregivers experience their involvement in involuntary admission as betrayal of the service user’s trust, we propose a more thorough investigation of the experiences of caregivers of those who were admitted to hospital involuntarily (Parker, 1993).

The following study took place in two countries with substantially different mental health legislations. In Ireland, there is one presiding form of mental health legislature for the entire country. In the United States, this legislature changes between states. The purpose of this study is to (1) examine caregivers’ reflections of their experiences during their relative’s admission and thereafter and (2) to assess whether these experiences may differ according to the process in which an individual is legally involuntarily admitted.

In this chapter, we provided a rationale for the qualitative study based on our observations during quantitative interviews. In building this rationale, we drew on available research, both old and new, to help us understand caregivers’ experiences from a qualitative angle with an emphasis on appraisals and emotional context. In our next chapter, we will describe the methods adopted for this qualitative study. It will, in particular, address how participants were recruited, the experiences and perceptions they were asked to recall on and how the interviews were conducted in each country. To help the reader, a summary of how civil commitment occurs according to Connecticut’s mental health law can be found in Appendix XXIX.
Chapter Seven

Methodology

7.1 Research Aims & Objectives

The aim of this study was 1) to explore caregivers’ experiences of their relative’s admission and illness in Ireland and Connecticut and 2) to observe whether these experiences differed according to the mental health legislation in each country. Caregivers were asked to elaborate on the positive and negative experiences of caring for their relative and their experiences within the hospital including their involvement with clinical staff and possible barriers to accessing treatment for their relative. A major component of the interviews focused on their perspectives on whether their relative experienced coercion and pressures and the extent to which they perceived the admission to be procedurally just.

7.2 Theoretical Framework

Qualitative interviewing was adopted for this study due to its ability to extract rich and meaningful narratives of individual caregivers’ experiences of the admission and caregiving (Sofaer, 1999). The study also adopted an interpretive framework whereby the focus of our questions and analysis was on creating a picture of what it is like to be a caregiver for an individual who requires admission for an acute episode of mental illness. This approach was selected as caregivers’ appraisals constituted of individual perceptions or subjective ‘realities’ regarding the admission. Data were collected by means of a semi-structured interview that allowed caregivers to articulate their experiences in their own words. Caregivers were provided with an opportunity to express the positive and negative aspects of the admission and illness as well as express anything they felt was crucial to the study that had not been asked in the quantitative study. The data presented in this thesis underwent a process of
triangulation by which both quantitative and qualitative findings were used to form a final conclusion.

7.3 Recruitment

Participants were recruited using two national mental health organisations which provide support to both caregivers and service users: Shine (Ireland) and the National Alliance on Mental Illness (NAMI). Advertisements pertaining to the study featured on the newsletter and website of Shine and by a forwarded internal email in NAMI in Connecticut. Using this method, 14 caregivers of individuals who had been involuntarily hospitalised for a mental disorder were invited to participate in an interview about their experiences of their relative’s admission(s). Individuals were excluded from participation if they were under 18 years of age, had a moderate-severe intellectual disability or if their relative had exclusively experienced voluntary hospitalisations. Minors were excluded as the mental health organisations involved in the study catered to adult caregivers. Individuals with a moderate-severe intellectual disability were excluded as the researcher had no experience in working with individuals with an intellectual disability. Finally, caregivers of those voluntarily admitted were excluded in this study as the literature (evidenced in our first chapter) revealed that service users who were admitted involuntarily more frequently highlighted perceiving coercion at admission. This last criterion led to two exclusions (see flowchart 2). Convenience sampling was used to recruit caregivers of service users who had previously experienced an involuntary admission in either Ireland or the state of Connecticut. Sample size was not predetermined prior to interviewing participants. Instead all participants who volunteered and who met eligibility criteria were included. The final sample size of 14 was considered appropriate for the approach taken (Guest et al., 2006).

7.4 Participants

Fourteen caregivers participated in the present study. Of these, 9 (64%) were Irish caregivers and 5 (36%) were caregivers from Connecticut. The Irish caregivers consisted primarily of
mothers (n=8, 89%) with one sibling (11%). The American caregivers were all mothers. All caregivers stated that their relative suffered from a schizophrenic spectrum disorder that led to an involuntary admission. However, this was not confirmed by a written psychiatric assessment such as the SCID. Furthermore, no further data is available for these caregivers with regards to demographic data, length of illness or length of caregiving to preserve anonymity as both sets of caregivers were recruited from a small pool of involved caregivers from each organization.

**Figure 5:**

*Recruitment of participants for Qualitative Study*

<table>
<thead>
<tr>
<th>Caregivers contacted through Shine/NAMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 Caregivers Responded</td>
</tr>
<tr>
<td>Excluded: 2</td>
</tr>
<tr>
<td>No history of involuntary hospitalisation in service users</td>
</tr>
<tr>
<td>14 Caregivers Participated</td>
</tr>
</tbody>
</table>

7.5 Procedure

Caregivers were supplied with an information sheet and consent form and an opportunity to ask questions with regard to the study. Caregivers who were unable to attend an interview in-person were asked to return a consent form and state their consent prior to the interviews. All caregivers provided written consent.
Interviews took place in Trinity College Dublin (n=1) or at a public location chosen by the caregiver, such as a quiet café (n = 8). Although all interviews were anticipated to occur in person, all Connecticut-based interviews took place by telephone due to adverse weather conditions and time constraints (n = 5).

7.6 Instrument

The research questions used in this qualitative study stemmed from both the MacArthur Admission Experience Interview and from topics which caregivers’ spoke of freely during the quantitative study interview process. The interview schedule arose from our overarching research question within the thesis: ‘How do caregivers perceive their relative’s admission to hospital?’ The questions asked were the following:

1. Please tell me about how [relative]’s admission happened.
2. Did you experience any difficulty in getting medical help for him/her? If so, in what aspect(s)?
3. Do you feel that [relative] had control over whether he/she was admitted? In what way?
4. Was it his/her idea to come into hospital?
5. How do you feel your relative was treated during the admission? (respect, fairness, concern, listened to)
6. Do you feel your relative was (1) forced into hospital? (2) Or threatened?
7. Upon reflection, do you feel there was a positive aspect to the admission? If so, what was it?
8. Is there any aspect of the admission that you are not happy with? If so, what aspect(s)?
9. We are just coming to the end of the interview. Is there anything which you feel you would like to say that we have not spoken about?
7.7 Data Analysis

Braun and Clarke’s (2006) model of thematic analysis was used as a theoretical model of analysis. Alternative forms of analysis were considered and excluded due to not fitting with our aims (i.e. framework analysis, discourse analysis) or due to time constraints (i.e. grounded theory). Thematic analysis was chosen for its ability to produce evolving themes from caregivers’ accounts from both inductive and deductive angles. This flexible approach also allowed us to compare the experiences of caregivers across different countries to understand their ‘realities’ of being a caregiver. This consisted of six phases. In the first and second phase, each interview was transcribed and coded by the researcher. Interviews were initially coded according to events. Codes were then compared across transcripts from which themes were then identified. In steps four and five, themes were classified and the meaning of each theme was explained (Braun & Clarke, 2014). In the final phase, themes were explained within the context of the caregivers’ experiences of their relative’s admission and illness. Finally, these themes were ordered in sequence according to a specified timeline (pre-admission, admission, during hospitalisation, post-discharge). This theme order emerged from the data as caregivers’ accounts were often divided according to their perceptions of experiences before the admission, at the admission and closer to the timing of the interview.

A total of 13 interviews were audio recorded and transcribed. One caregiver did not consent to audio recording. In this instance, contemporaneous researcher notes were employed as an alternative option. The interviews lasted between 30 minutes to an hour and a half. Computer Assisted Qualitative Data Analysis Software (CAQDAS) was not used in this study both due to the researcher’s preference for simpler tools (MS Word) and due to the potential bias of using such tools with just one coder (Auld et al., 2007). Data was not fully cross-checked due to limited access to senior researchers with qualitative experience.
7.8 Reflexivity

I, as the sole interviewer on the study, kept a journal with entries regarding each interview. The entries included my subjective experiences of how factors such as my own previous mental health service use and my position as mental health researcher may have impacted what caregivers disclosed to me during the interviews. Although the former was not disclosed during these qualitative interviews, it may, unconsciously, have affected how I perceived and subsequently analysed the transcripts. Such disclosure, however, was not made to caregivers for fear that it may bias their responses. Furthermore, unlike the quantitative interviews, I was not affiliated to a mental health service for the purpose of this qualitative study and, therefore, interviews did not occur on hospital or clinic grounds. As a result of both, it is less likely that caregivers viewed the interview as an opportunity to improve or affect their relative’s outpatient care. Additionally, as almost all caregivers in this sample were mothers, I was aware of a significant age and experiential difference between the interviewer and interviewee and, at the time, was conscious of whether such differences may impact what they choose to disclose.

Most importantly, I feel it is necessary to note that I am not clinically qualified. Although I might have felt that the interviews provided a therapeutic outlet for caregivers, I sometimes also questioned the ethicality of conducting interviews with a vulnerable population as it posed a risk of causing anxiety and distress (Richards & Schwartz, 2002).

7.9 Ethical Considerations

This study received full ethical approval from the School of Psychology, Trinity College Dublin. The researcher filed for an exemption for the study from Yale University’s Human Investigation Committee review on the grounds that the present study did not represent “research involving the use of educational tests, survey procedures, interview procedures or observation … obtained and recorded in such a manner that the human subjects can be identified, directly or through identifiers, linked to the subjects; and any disclosure of the
human subjects’ responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects’ financial standing, employability, or reputation” (Request for Exemption from Committee Review Form FR 9, 2013 - 1). However, the director of Yale University’s Programme for Recovery and Community Health governed that the approval received by Trinity College Dublin was “considered appropriate to address the human rights issues involved in conducting these interviews with members of a community based organization that has no formal relationship to the university” (Please see Appendices VII-IX). Additionally, as requested by Yale University, the researcher underwent Health Insurance Portability and Accountability Act (HIPAA) training and training from the National Institutes of Health (NIH) on ‘Protecting Human Subject Participants’. Such training was completed in order to ensure that key ethical issues and procedures relating to informed consent, risk and anonymity were understood and preserved.
Chapter Eight

Results

The results presented here are divided according to timeline and common themes. Caregivers were asked to portray their experiences prior to the service user’s admission, from the admission, from the hospitalisation and after the service user’s discharge from hospital. At the start of each interview, caregivers were asked to provide a description of the lead up to their relative’s admission. In summary, noticing a deterioration in the service user’s health led to a growing concern for both the service user’s wellbeing and the caregiver’s own safety. It is this concern that most often led caregivers to seek help and, in turn, resulted in the service user’s admission. Although caregivers’ perceptions of admission were central to this study, caregivers were most vocal about their relative’s treatment and support during hospitalisation and upon discharge. The themes extracted from the transcripts are presented in the table below.

Table 19.
Themes extrapolated from transcripts of qualitative interviews

<table>
<thead>
<tr>
<th>Caregivers’ Experiences</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Experiences prior to Admission</strong></td>
<td>Deterioration in the service user’s health</td>
</tr>
<tr>
<td></td>
<td>Growing concern of caregiver</td>
</tr>
<tr>
<td></td>
<td>Seeking help</td>
</tr>
<tr>
<td><strong>Experiences of Admission</strong></td>
<td>Entering hospital</td>
</tr>
<tr>
<td></td>
<td>Perceptions of coercion, pressures and procedural justice</td>
</tr>
<tr>
<td><strong>Experiences of Hospitalisation</strong></td>
<td>Perceptions of treatment</td>
</tr>
<tr>
<td><strong>Experiences upon Discharge</strong></td>
<td>Recovery</td>
</tr>
<tr>
<td></td>
<td>Accessing outpatient care</td>
</tr>
<tr>
<td></td>
<td>Supporting the family</td>
</tr>
<tr>
<td></td>
<td>Preparing for re-admission</td>
</tr>
</tbody>
</table>
8.1 Experiences prior to admission

*Deterioration in the service user’s health*

Admission to a mental health hospital was preceded by a noticed deterioration in health, or an accumulation of visible symptoms of an illness. In many scenarios, these symptoms took the form of delusions and hallucinations, high levels of anxiety or insomnia and unusual behaviour. In others, absconding and suicidality were noted in the service user. Some caregivers noted that admission re-occurred once the service user stopped taking medication and missed medical appointments. Relapse, in this case, was attributed to the service user’s own denial of the illness. In such cases, self-medication by means of alcohol or substance use was a common narration of caregivers.

“He was so psychotic and delusional that he believed he was the president of the United States and he left our home and we found him after several hours standing in the neighbour’s yard under a tree.” (Audrey, Mother)

“He was very agitated and he wanted to die because he couldn’t cope with these voices and they were warning him that terrible things were going to happen.” (Rachel, Mother)

“She had taken off to California with no money and no identification, was wondering the streets of LA.” (Gabriella, Mother)

“He would be in denial of his illness. He would stop taking his meds or he would stop going to his therapist or he would not meet his doctors’ appointments.” (Carly, Mother)

*Growing concern of caregivers*

All caregivers reported a growing concern for the service user following the appearance of symptoms. This concern stemmed from the threat of “self-harm” or the presence of aggressive behaviour due to the illness. Retrospectively, many caregivers conveyed that they felt something was amiss when their relative’s first symptoms of mental illness appeared but...
felt unable to pinpoint the exact cause. Being unable to decipher what was wrong led to caregivers not knowing what actions to take. A minority of caregivers identified that the unusual behaviours corresponded to a mental illness and required immediate medical attention. For others, a friend or mental health professional was the first to outline that a mental illness was the root of their relative’s decline in well-being.

“He was very psychotic, very aggressive. He was a danger to others. He attacked his father, he attacked my husband, which is totally out of character.” (Anna, Mother)

“I had a sister who suffered from mania or bipolar. I knew from that experience that my son wasn’t going to be manageable at all at that time.” (Siobhan, Mother)

“One of his pals in the house, his mother was a psychiatric nurse and ... thought that something was the matter from listening to the descriptions of him ... it was like a ton of rock landed on my head you know.” (Imogen, Mother)

Seeking help from external services
This growing concern for the service user’s wellbeing and the caregivers’ own safety often triggered help seeking. Caregivers sought admission when they perceived that service users were unable to look after their wellbeing or were not in control of their own actions. Caregivers who witnessed their relative’s first episode of illness stated that they had difficulty knowing who to initially contact during such an emergency. Prior to the admission, all caregivers sought help for their relative from the health service, the police department or both. One caregiver developed a trusting relationship with the police department who facilitated each admission to hospital.

“We realized this was somebody who could no longer really care for herself.” (Gabriella, Mother)
Many caregivers recounted having difficulty getting adequate medical attention for their unwell relative. These barriers to treatment primarily focused on the refusal and reluctance of the police force and medical health professionals to admit the individual to hospital. This difficulty was more accentuated when help was sought after work hours. Caregivers commented that this reluctance may have been due professionals not seeing the gravity of the illness and feeling pressured to not admit more individuals due to a shortage of hospital beds. In one case, the service user was brought to hospital repeatedly and sent home with new medication which, according to the caregiver, did not bring any amelioration in symptoms.

“The need for admission often happens at night or after hours when the GP is out, the doctor on call doesn’t show up and the guards tell you that it’s none of their business.” (Breda, Mother)

Basically, I felt if you’re not hanging out of a rope or swinging a hatchet around town, there’s no bed for you. That’s the way it is now in the psychiatric services.” (Rachel, Mother)

“We had been to the hospital twice before that and they kept giving a new medication ... and send me home with him and and it wasn’t working and just it was, he wasn’t getting any better.” (Barbara, Mother)

Caregivers expressed difficulty gaining medical attention from both the mental health and police services that failed to listen, provide guidance and recognize the need for their relative’s hospitalisation. Caregivers, at times, reported having to advocate for their relative in order to receive adequate medical attention from the services. When the severity of the
service user’s illness was acknowledged, caregivers reported feeling justified. One caregiver continued to state that this help was only offered based on the caregiver’s ability to advocate for their relative.

“Yeah, I felt I had to really strongly advocate but ... I felt really vindicated when the consultant ... rang me and said ‘he is really, really sick. We have to keep him’...“I met an older woman. She was really vulnerable because she wasn’t in a position to advocate for herself and for her son.” (Barbara, Mother)

“The most difficult ... for us is the inability to get people to respond properly. When we called 911, the police officer showed up ... deemed him well and umm cancelled the ambulance from coming ... I was told until he walks through the doors of the hospital there’s nothing they can do to help me.” (Audrey, mother)

Some of the barriers experienced by caregivers were attributed to shortcomings or loopholes within the country or state’s residing mental health legislation. In Ireland, two Irish caregivers reported that they experienced a significant barrier to treatment for their relative due to disagreement or lack of coordination between mental health services. One of these referred it to a dispute between the public and private tiered mental health services regarding who should treat the service user. These disputes led to considerable distress and worry in both caregivers. In Connecticut, one caregiver expressed frustration over not being able to avail of services for her relative due to not living within the allocated catchment area of the mental health service.

“There was a public vs private dispute for his care. He was walking the streets for two nights while the public and private hospitals fought over his care.” (Breda, Mother)

“If I had lived in the area where I work then it seems that half the time it would have been a matter of making one phone call because the resources are there.” (Audrey, mother)
Caregivers reported that a considerable barrier to treatment was linked to their relative masking their symptoms during medical assessments. As these medical assessments were short in nature, caregivers expressed that service users were able to suppress demonstrating symptoms in order to avoid admission. Admissions, therefore, tended to occur once the illness reached a crisis point where symptoms could no longer be hidden.

“He can appear fine for 15/20 minutes. He can pull it together for that amount of time. It was clear within two hours that he was psychotic.” (Breda, Mother)

Not all barriers to help-seeking were linked to external services. For example, in one instance, a caregiver cited that a family member’s lack of understanding or misevaluation of the gravity of the situation was a significant barrier to help seeking. This misunderstanding led to escalated harm. When help was eventually sought from the emergency services, these were not available immediately and the service user’s parents had “to restrain him.”

“I called my husband and I said ‘please call 911’ ... and my husband didn’t understand that I was 100% serious and when I drove in and he (son) jumped out of the car ... the first sharp thing he found was a knife and proceeded to start stabbing himself.” (Audrey, mother)

8.2 Experiences at Admission

**Entering hospital**

Caregivers reflected on the admission(s) both positively and negatively. For many, this experience was distressing and traumatising at each admission as they felt disheartened by leaving a relative in hospital against their will. For some, admitting their relative required extensive persuasion of the services and of the individual when he or she lacked insight into their illness. This, in turn, affected the relationship the caregiver shared with the service user, with many citing a breakdown in communication afterwards. When admission was led by someone external to the family, families expressed relief over a prevented rupture in their relationship with the service user.
“I was very heavy hearted leaving the hospital. That’s the thing that the parent always feels, that you’re letting down your child you know.” (Imogen, Mother)

“I have to explain the situation every time and it’s extremely embarrassing and traumatising for us. It’s a ‘favour’. It’s humiliating and embarrassing .... A member of the public called in once. I felt relieved it wasn’t us that time. When he recovered, we could face him and tell him we had nothing to do with it.” (Breda, Mother)

“He didn’t want to talk to me once admitted.” (Alexis, Mother)

Caregivers, however, also stated that they experienced relief upon admission once they were reassurred that their relative was in a safe environment and was being cared for by professionals as well as respite after a prolonged period of looking after the service user when he or she was acutely unwell.

“When he was gone in ... there was a relief there for me, he’s gone, he’s gone, he’s getting help now.” (Barbara, Mother)

“Respite for me but it was also help for him. I mean things had just reached the limit.” (Imogen, Mother)

Caregivers’ experiences of the admission were divided between two settings: the home and the hospital. Some caregivers recalled that a medical team arrived and initiated the admission at their relative’s house. Although these caregivers tended to play a less active role in the admission due to being underage at the time of admission, their memories of the admission are striking and reveal an element of trauma.

“I just remember that the people in white coats arrived and ... my uncle ... took me for a walk down the garden while she was brought off in the hospital.” (Jennifer, Daughter)
“I remember one particular time ... she locked herself in her room ... they had to physically push the door in ... which was quite upsetting.” (Beatrice, Daughter & Sister)

The majority of caregivers reported that their main experiences of admission occurred at the hospital. Caregivers indirectly questioned the validity of current mental health policy in helping their relative receive appropriate care. For example, caregivers questioned the usefulness of approaching the service user’s general practitioner in order to initiate an involuntary admission (as prescribed under the Irish Mental Health Act 2001) rather than directly contacting a mental health centre previously attended by the service user. Furthermore, caregivers criticised both the appropriateness of using the accident and emergency section of a hospital in dealing with a mental health crisis and the need for a full medical assessment in service users who are acutely mentally unwell and have a standing history of mental illness.

“Why do we have to bring her to a doctor first, then take her up to a hospital to be assessed? Why couldn’t we just bring her directly to where they know her history?” (Barbara, Mother)

“The problem then is you have to go to a general A & E department. I was nervous if he lost the head for want of a better word ... and that other people could be frightened. They were already watching him pacing in and out all the time.” (Rachel, Mother)

**Perceptions of Coercion, Pressures and Procedural Justice**

When caregivers were asked whether they felt their relative was coerced at admission, many recounted that the service user did not have control over the admission due to the severity of his or her illness. Caregivers predominantly viewed their relative’s admission as forced and imposed by them rather than the service user or the mental health services. They also uniformly expressed that the service user was not threatened into admission by anyone involved. Furthermore, caregivers stated that service users did not choose to be admitted nor did the idea originate from them.
“It was not his idea. Our family said it but he previously wouldn’t have considered it.” (Breda, Mother)

“As I’m leaving he’s crying out ‘mom why you doing this to me? I don’t want to be here, don’t leave me here’.” (Carly, Mother)

“Did they force him? No ... it was always my doing, the forcing.” (Sophie, Mother)

“Threaten her no. I can honestly say I would never ever see that.” (Gabriella, Mother)

Caregivers accounts of treatment at admission tended to vary. Some caregivers reported that their relative was treated fairly and respectfully during the admission. Those admissions which were viewed in a positive light were characterised by the staff’s generosity, patience and kindness towards the service user. Those who viewed the admission process as negative, described it as clinical and devoid of compassion. Others felt that the quality of the care their relative received and caregiver interaction was poorer if their relative was admitted to a public rather than private hospital.

“I think they have been more than generous .... They’re very patient with him considering ... he’s abusive to them” (Anna, Mother)

“I don’t believe he was treated well at all because he was left out on a gurney in the hallway of the emergency room.” (Carly, Mother)

“There was no room or space for any kind of compassion. It was like looking for signs of his madness you know.” (Imogen, Mother)

“In the private hospital, I feel he is listened to. He is treated with dignity. The public hospital was drastic. I am totally unhappy with it. There is no dignity for the patient. The hospital had
totally inadequate visiting hours. It was like a prison. It was filthy and the family is treated with suspicion.” (Breda, Mother)

Some caregivers felt unsatisfied by the system of admission or pathway to care as opposed to any specific individual at admission. Furthermore, some caregivers reported that although they felt their relative was treated fairly, it was not always possible for them to always be listened to by the admitting mental health professionals due to a distortion in reality caused by the illness.

“I couldn’t complain in any way about his treatment once the admission had been decided you know and no individual in the system at any time. It’s the system itself.” (Rachel, Mother)

“There’s a point if a person is really high and really like for the birds literally, I don’t know how you can really listen to that.” (Imogen, Mother)

Almost all caregivers reported that their relative was forcibly psychologically or physically hospitalised. Only one caregiver reported that the service user was “persuaded” rather than forced during the involuntary admission. Caregivers stated that the admission was necessary and justified adopting these coercive practices out of fear that the service user would harm or suffer an further decline in health. For many, this use of coercion was linked to the service user’s lack of insight into his or her illness.

“He was involuntarily admitted. He was forced, psychologically forced. I feel he wouldn’t have lived if we hadn’t done that. He was in imminent danger but he’s alive.” (Breda, Mother)

“She was definitely forced and she never wanted to go in. She doesn’t think there’s anything wrong with her.” (Sinead, Daughter)
“At one point ... she was chased around the housing estate. She was literally dragged back and brought in kicking and screaming. It was forced but it was necessary.” (Jennifer, Daughter)

All of the caregivers in this sample reported that their relative was “never threatened” into being admitted into hospital. One caregiver, however, thought their relative felt threatened by the individuals with whom he shared a secluded ward.

“In the lock up unit I think he felt very threatened ... because he was in with people who were taking drugs or kind of dangerous kind of people.” (Barbara, Mother)

8.3 Experiences of hospitalisation

Perceptions of Treatment

Caregivers of service users who had multiple instances of hospitalisation tended to describe both positive and negative experiences of admission depending on the services the service user attended. Caregivers’ accounts of positive experiences of hospitalisation focused on both the service user returning to health and the caregiver receiving respite. Caregivers noted that hospitalisation allowed the service user to recover. Some caregivers found that the mental health services their relative attended were helpful and attentive to the service user’s needs. Importantly, these instilled a sense of hope in caregivers. This return to health was also aided by the structured environment and routine of the hospital. One caregiver stated that the hospitalisation allowed her to recognize the extent to which her relative needed care following discharge. However, caregivers who were adult children of the service user tended to express that their relative’s recovery was underpinned by a desire to leave hospital rather than an improvement per se.

“We got our son back. If he had not been hospitalized and if the current medication had not been found, I assure you he would have lived the rest of his life in an institution. It was a huge benefit to him to be hospitalized.” (Audrey, Mother)
“I would get respite. He had a structured living environment that he needed to be in. He was on a routine.” (Sophie, Mother)

“I think a lot of my mother’s ‘recovery’ would have been down to the fact that she needed to pull herself together in order to come home.” (Jennifer, Daughter)

Others, however, felt that the services dismissed and ignored both the service user’s and the caregiver’s needs. One caregiver recalls that the mental health services neglected to thoroughly investigate the cause of her son’s illness. Furthermore, the same services which were involved in her son’s care failed to apologise for their neglect after years of misdiagnoses. In another case, the caregiver felt that the treating mental health team was not aware of the extent of the relative’s illness “because he was quiet” and “quiet was seen as ok’. A proportion of caregivers stated they were dismayed by the lack of availability of other mental health professionals other than psychiatrists. These caregivers expressed that it was not the mental health professionals who were to blame for a reduced level of care but the lack of employed mental health professionals in the mental health services.

“He was treated differently in different facilities … the better places I think they treated him wonderfully. He was happy when he left. He was, he felt like a new person.” (Carly, Mother)

“I would always ask the nurse and say ‘do people ever come out of this?’ And they always told me ‘yes’.” (Imogen, Mother)

“I was given the diagnosis I was screaming about for thirty-three years… If anyone would have just said to me ‘I’m sorry’.” (Sophie, Mother)

“The psychiatric services have been decimated of nurses in the community and psychiatric nurses…It’s not the person doing the job. It’s the lack of people doing the job.” (Rachel, Mother)
Caregivers expressed concern over the short-term treatment of mental illness in hospitals and dismay over not gaining further help for their relative. Some noted that they had to advocate for the service user’s needs at a time where they felt the mental health services were not paying attention. Two caregivers acknowledged that they were able to gain the help of “top-notch psychiatric hospitals” only by availing of premium insurance. Caregivers noted that the care received by the service user depended on the relationship their relative had with his or her treating clinicians. When the therapeutic alliance between the clinician and the service user was absent, the service user was dismissed by the mental health services. Caregivers also revealed some concerns about the use of medication. For some, the process of recovery was induced by the use of medication which effectively reduced visible symptoms. Others, were concerned about the side effects of medication and felt that the mental health services were resistant to providing other forms of treatment other than medication. Medication, in itself, was viewed as a useful form of treatment that bore significant side effects. Some caregivers, however, expressed “difficulty understanding the treatment plans” or disagreed with the treating clinician’s use of polypharmacy.

“If it wasn’t me digging in there... he probably would have never gotten a toothbrush.” (Carly, Mother)

“Some of them they really connect with and therefore the relationship is solid. Others they dismiss and discharge.” (Gabriella, Mother)

“Within three weeks of taking the clozapine I could see a change in him. I could see like he was more alive and more present and you know just more alert and everything.” (Imogen, Mother)

“One doctor just kept prescribing intensive medications to the point where he was taking ... maybe eight different types of antipsychotic medication.” (Carly, Mother)
“I’d make it nearly a requirement of … the services that they have to engage in some sort of … therapy besides medication.” (Anna, Mother)

“He was in crisis, was given meds and then was sent back out. He should have been treated in hospital for at least a few days. It’s like a band-aid practice.” (Alexis, Mother)

8.4 Experiences following Discharge

Recovery
Caregivers expressed that their experiences post-discharge consisted of both positive and negative aspects. Although many experienced and appraised the period after discharge as difficult, positive accounts were attributed to a return to wellbeing and the service user leading a ‘normal’ life following discharge. A proportion of caregivers expressed that their collective experiences of their relative’s hospitalisations led them to find “a lot of good people in the service” and feel more familiar with the mental health services and comfortable in knowing that they could “trust them and trust their judgement”. Caregivers’ negative accounts of caregiving, nevertheless, often arose when the service user was extensively impaired by the illness that caused him or her “to not be able to hold down a job”. In these accounts, caregivers felt apprehensive that the service user was discharged prior to making a full recovery and dismissed after bringing their concerns to their relative’s treating clinician’s attention. In one instance, a caregiver conveyed that their relative was discharge during an acute episode of illness.

“Since then he has a wonderful life with a partner. So my son … he is a functioning person with mental illness.” (Carly, Mother)

“He was pushed out earlier than he should have been. One time … he had been discharged and he became so psychotic in the car we had to drive him directly to his psychiatrist’s office and have an emergency visit.” (Audrey, Mother)
“After he left hospital ... he wouldn’t leave the car for me, he wouldn’t get out, he was completely paranoid about people on the street.” (Barbara, Mother)

“‘Well he’s discharged like. If you don’t take him, he’ll just be going anyway’. His father... was really shocked...by the dismissiveness of the consultant.” (Rachel, Mother)

**Accessing outpatient care**

Following discharge from hospital, caregivers expressed difficulty acquiring outpatient treatment for their relative. The lack of available after-care for their relative caused them significant distress as they felt it prevented their relative from conducting a ‘normal’ life which consisted of leaving the house for activities, acquiring a job and engaging with their community. This was further amplified by the significant side effects of the medication prescribed by the mental health services that were viewed as debilitating to the service user’s health and ability to interact with their environment. This paucity of care was, at times, due to not living within a specialist’s catchment area or the service user’s refusal to accept treatment. Caregivers who were redirected to the service user’s family doctor for post-discharge care did not find this useful. In one instance, outpatient treatment was not offered due to a dispute between the private and public healthcare sector which was eventually legally addressed.

“He didn’t have follow through and was put on the streets after his hospitalization ... There aren’t enough day centers where a person with mental illness can have companionship or some normalcy. He would otherwise spend all day long in his apartment. Nothing ... to get him to function in society, no follow through to help him get a job either.” (Alexis, Mother)

“He came home and was in a catatonic state from one of the medications. There are side effects to every drug. He gained a lot of weight and is now diabetic”. (Alexis, Mother)
“There’s no point sending him back to his GP. His GP hasn’t seen him in three years. What will his GP know about his psychiatric medication? For God’s sake that is ridiculous.”  
(Rachel, Mother)

“My son never had outpatient support for three or four years ... We had to appeal that any patient has a right to follow-up to the ombudsman. It had to go to that level.”  
(Breda, Mother)

Caregivers also revealed that service users failed to receive ongoing outpatient treatment due to their own refusal to engage with the mental health services. This refusal was partly due to feeling disrespected by mental health professionals within the services who were not viewed as caring, attentive and client-centred. Other caregivers reported that their relative refused to attend the services that were offered due to their own stigmatising beliefs of other service users who attended these.

“They’ve got five minutes with you. There’s no rapport. They’re trying to get the information in as quick a time as possible but it’s very distressing for the person visiting.”  
(Imogen, Mother)

“He told me that he wasn’t going down there to drink coffee with burnt out schizos.”  
(Rachel, Mother)

Caregivers articulated that they felt there was a gap in care between hospitalisation and independent living that needed to be bridged, which they referred to as an “intermediary support structure”. They frequently demanded information regarding available mental health services following discharge and asked “where do you go for what?” One caregiver who became a mental health nurse as a result of her relative’s illness expressed sadness over not being able to locate information despite working in the field.
“There’s no solid … transitional arrangement between hospitalization and trying to live on your own.” (Gabriella, Mother)

“Sadly with my resources and all my my contacts...you have to really ask and really dig to get the information you want.” (Audrey, Mother)

Some caregivers found outside support useful in helping them understand their relative’s illness and what to do in the event of a crisis. In return, some of the caregivers interviewed were involved in providing that form of support to other caregivers with an emphasis on contacting emergency services when necessary “to get them (service users) safe and ... keep yourself safe”.

“I run the support group ... and we talk about hospitalization, we talk about the good ones and the bad ones and so hopefully I’m educating them as to you know you really have to look out and find the right facility for your needs.” (Carly, Mother)

Two Connecticut-based caregivers legally applied for conservatorship to support the service user with their personal and financial affairs while they were unwell. Caregivers recounted that this was met with anger and resentment by their relative due to a legal revocation of their independence. These feelings also led to a breakdown in the caregiver’s relationship with their relative that, in one case, lasted for several years.

“We had really been at loggerhead with our child since her 20s. It caused a lot of bitterness and anger on her part but then she herself has said because she was in such a bad place it more or less saved her life.” (Gabriella, Mother)

Others, however, narrated that their relationship with their relative improved to the extent where the service user trusted the caregiver to tell him or her “when he’s not feeling good or he just needs me to be his advocate again”. One caregiver proudly remembered that their
relative provided that support to other service users where “he advocates for others who have a mental illness”.

**Supporting the Family**

Most caregivers expressed a desire to be involved in the service user’s care. Caregivers expressed a need for sharing information in order to maximise their relative’s treatment. Caregivers expressed a need both to inform the services of the service user’s history of illness and circumstances at admission as well as receive information to help bring about recovery for the service user and the family as a whole after discharge.

“*I think they need to know what’s going on rather than rely on the service users themselves…especially if they’re really very distressed. Someone needs to make a phone call … and say ‘from your point of view what is going on?’.*” (Anna, Mother)

“*If the family could be more involved … it would be a more well-rounded approach to recovery and the whole family could recover then as a result because the whole family is affected by it, not just the service user.*” (Jennifer, Daughter)

Many caregivers stated that the service user’s right to confidentiality prevented them from receiving information that they felt would help them take care of their relative. Some disclosed that this clause was being adopted purposively to inhibit family involvement. Furthermore, a sub-section of these caregivers stated that being denied access to such information went against their rights. On one occasion, the reluctance of a clinician to share information regarding the scheduling of clinical appointments led to the her relative missing these appointments and being dismissed from the services.

“*I know confidentiality is a huge thing … but families do need to know what medication needs to be taken and when because … it falls on the family to look after them.*” (Jennifer, Daughter)
“I think the confidentiality clause has often been used ... as a way of not engaging the family. We have to feckin’ live through this, do you know what I mean?” (Anna, Mother)

“The carer who is doing 90% of it has actually no rights.” (Rachel, Mother)

Feeling unsupported was a common complaint by all caregivers. For some, this was linked to an excess in responsibility and a lack of support within the family structure. However, for many, this lack of support was linked to a lack of guidance and protection from the mental health services. One caregiver found, from personal experience, that the availability of an intermediary health professional was a good solution to bridging the gap between the mental health services and the family.

“His dad couldn’t handle him anymore and sent him packing up to me.” (Imogen, Mother)

“I don’t even think the carers are being protected from violence.” (Rachel, Mother)

Caregivers acknowledged that external stigma prevented them from receiving support. A need for acceptance and knowledge of mental illness was suggested as a method of combating stigma in society. Caregivers highlighted that this process should be initiated at a young age in schools. Many caregivers also spoke of the value of education in informing individuals of what to do during a mental health emergency and what mental developmental landmarks should parents expect to observe during their each stage of their child’s youth as a guideline.

“It’s like suddenly you have cancer you know. There’s cancer around. It’s like something unknown that people are afraid they’re going to catch ... It has to come out in the open. There has to be education in primary school ... to be able to recognize symptoms and recognise some people are incredibly vulnerable.” (Imogen, Mother)
Despite searching for acceptance of mental illness within society, caregivers tended to blame themselves for not intervening sooner or recognising the symptoms of their relative’s illness. They also expressed regret how much their relative’s life differed from the caregiver’s hopes, a sense of obligation and hopelessness. Supporting the

“Maybe if he had been sectioned before... or detained a little bit longer it might have made ... a better outcome.” (Anna, Mother)

“I should have twigged something ... Now in his 30s he’s missed so much...If somebody waved a magic wand and he was normal in the morning, how do you regain 14 years of maturity and development that he has never experienced?” (Rachel, Mother)

Finally, caregivers emphasized a need for increased public spending on mental health services and raising public awareness of mental illness citing that many individuals receive inadequate care that is delivered in substandard premises. One caregiver, however, acknowledged that there is an increase in American governmental effort in mental health due to the many violent tragedies that have occurred that were linked to mental illness. Multiple caregivers also highlighted the importance of medical insurance in providing good treatment for their relative and the affordability of such. One caregiver reflected on the value of new governmental policy in facilitating mental health treatment.

“There’s more of an effort ... because of so many violent activities that we see in the last 10 or 15 years ... There’s not enough money... to really give the care to some seriously ill people that’s needed. Most of our hospitals are prisons. There are too many people who really are left on their own.” (Gabriella, Mother)

“Insurance didn’t cover so many things. What do people do if they don’t have good insurance other than file for disability? (Alexis, Mother).
Prepending for the possibility of future admissions

Caregivers highlighted the possibility of future admissions. In doing so, some stated a desire for crisis planning and helping service users feel less nervous about admission by letting them familiarise themselves more comfortably with hospital settings and choosing their own admitting preferences by means of advanced directives.

“Patients should go back to the ward ... to walk around when well so as to desensitise the person so that you’re not terrified ... There should be a record. I want a designated local guard to call and I want these people to be introduced to him – familiar faces – so that he’s not frightened. I want to have a card as part of his care plan that says ‘this person will be called, even when unwell, you will trust this person’.” (Breda, Mother)

This chapter outlined the experiences of both Irish and Connecticuter caregivers. These have centred on their experiences of caregiving prior to admission, at the admission, during hospitalisation and after discharge. In the next chapter, the discussion, the relevance of these findings and the extent to which these coincide with earlier research will be considered. The implications emerging from our results will be highlighted and the strengths and weaknesses pertaining to our study discussed. In light of these findings, ideas for future research will be suggested.
Chapter Nine

Discussion

This final discussion will, firstly, summarise the findings of the qualitative study examining the experiences of caregivers of involuntarily admitted service users both in Ireland and Connecticut. Secondly, in doing so, it will highlight any discrepancies in experiences between the two groups and compare these findings to those present within the literature. This chapter will then describe the theoretical and practical implications of our findings and discuss the strengths and weaknesses pertaining to this study. Finally, it will suggest topics for future mental health caregiver research.

9.1 Summary of Findings

Our findings were divided according to the timeframe in which they occurred. Although the focus of our study was on understanding the admission from a caregiver’s viewpoint, caregivers spoke of their experiences from different timepoints. The researcher therefore felt it was clearer to structure the analysis following a chronological order. The timeframes referred to events that occurred prior to the involuntary admission, during the admission and hospitalisation and events that occurred at or following discharge from hospital. Additionally, caregivers expressed their needs and feelings regarding the overall experience of their relative’s illness. Prior to admission, caregivers reported a deterioration in their relative’s health accompanied by an accumulation of visible symptoms or unusual behaviour. Although many caregivers noticed this deterioration, a significant proportion of them reflected that they were in denial of their relative’s illness. These caregivers reported that they initially did not wish to believe that their relative was ill or did not wish to fulfill a caregiving role to a mentally ill individual. Despite this denial, all caregivers reported a growing concern for their
relative’s well-being upon witnessing symptoms. Many caregivers cited that they knew something was amiss with their relative’s health but were unable to pinpoint the source of illness. A minority recognized that their relative’s symptoms were a representation of a mental illness due to witnessing similar manifestations of symptoms in other relatives.

Caregivers who feared that their relative was at risk of harming themselves or others intervened to initiate help-seeking. However, knowing who to contact for help was viewed as a significant barrier for caregivers who often resorted to seeking help from their family doctor or the emergency services. Help-seeking was, at times, met with a reluctance and refusal to cooperate from professionals and mental health services who disputed over the service user’s care or failed to recognize the need for hospitalisation. Moreover, caregivers reported taking an advocacy role to ensure that their relative received the in-patient treatment they felt was needed which was particularly difficult when their relative masked their illness to discourage health professionals from signing an admission order.

Caregivers generally experienced their relative’s admission as a traumatic and distressing event. It was associated with relief and respite in the knowledge that the service user was receiving treatment and was safe from harm. Conversely, it was also associated with feelings of guilt and led to a breakdown in their relationship with the service user who did not want further contact. Caregivers who pursued a conservatorship of person and estate during their relative’s admission were particularly impacted.

Caregivers were discontent with the pathways to care available to them and their relative. Those whose relative had a long-standing history of mental illness questioned the need for them to repeatedly involve either the probate court or the family doctor in re-instating an admission order. Furthermore, families that needed emergency care after hours and had to resort to their local hospital for immediate care were outspoken about the incompatibility of the emergency department’s practices when handling a crisis involving an individual with an acute episode of mental illness. Long waiting times in general hospitals in proximity to individuals unfamiliar with serious mental illness were viewed as further stress-inducing for
caregivers of individuals who were floridly psychotic at the time of admission. Full medical assessments as a requirement for hospitalisation (in particular blood tests in service users who were suffering from tactile hallucinations or needle-specific phobias) were viewed as unhelpful and mistimed by caregivers of individuals who had been hospitalised for an acute mental illness on multiple occasions.

Caregivers predominantly stated that the service user did not have control and did not choose to be admitted nor was admission their idea at the time they were admitted. Caregivers revealed mixed perspectives on their relative’s admission. Those who felt their relative was treated fairly and respectfully at admission associated these perspectives to health professional’s patience, generosity and kindness. Those who felt their relative was treated unjustly attributed this perception to the staff’s clinical coldness and lack of compassion for their relative’s suffering. Although many caregivers reported that their relative was treated fairly, some also stated the service user was not listened to at admission. This was excused by family members who felt that their relative was making disjointed or incomprehensible utterances due to their illness. All but one unanimously reported that their relative was psychologically or physically forced into admission, often by the family. One reported that their relative was strongly persuaded into admission despite their involuntary status. These coercive practices were justified by family members who perceived that their relative needed immediate and intensive treatment. Nevertheless, families reported that the service user was never threatened into admission but, in some instances, felt threatened by other service users who were acutely unwell during their period of hospitalisation.

Families perceived the service user’s hospitalisation as an opportunity for recovery that was aided by a structured environment and routine within the hospital. In some cases, recovery was perceived as underpinned by a desire to leave hospital. Caregivers disclosed mixed perspectives on the effectiveness and helpfulness of their relative’s treating team. Those who perceived the service user’s treating clinician in a positive light stated that they developed a positive relationship with their relative’s consultant that was characterised by respect and earned trust over time. Negative perceptions of hospitalisation centered on caregivers’ reports
that mental health professionals were unaware of the extent of their relative’s illness and
dissatisfaction with the lack of available psychologists and nurses in hospital. These accounts
often arose when the service user was extensively impaired by their illness and could not
retain a ‘normal’ life balance. Caregivers recognized a need for their relative to be medicated
when acutely unwell but expressed concern for the side effects induced by pharmacological
treatment and the reluctance for mental health professionals to integrate other forms of
treatment (such as talking therapy) into their relative’s recovery plan while in hospital.
American caregivers expressed dismay at the short length of their relative’s recurrent
admissions and quality of treatment, which only improved upon access to private insurance.
Some also disagreed with their relative’s treatment plan which, in one case, solely consisted
of polypharmaceutical treatment.

Discharge represented a particularly challenging time for caregivers who held predominantly
negative views of it and the period immediately after it. Many caregivers reported that the
service user returned home too early, before (positive) symptoms had fully abated and
without making a full recovery. Some families reported that their relative was unable to re-
stabilise over a short period of hospitalisation and remained afraid of hospitals. Upon
questioning the motives for their relative’s discharge, caregivers’ feel they were rejected and
dismissed by the mental health services who were unconcerned with their needs and capacity
to care for their relative. Caregivers articulation that they felt there was a gap in care between
hospitalisation and independent living. They also highlighted that they experienced
significant difficulty in acquiring outpatient treatment for their relative, either due to the
unavailability of treatment within the catchment area in which the service user resided or due
to the service user’s refusal to engage with the mental health services. According to
caregivers, this refusal was, in part, due to the service user’s stigmatizing beliefs regarding
other individuals attending the services and This sense of denial, however, was also portrayed
in other studies (Karp & Tanarugsachock, 2000). It was also accentuated by not feeling
respected within the mental health services by professionals who failed to provide supportive,
attentive and client-centred care.
Caregivers highlighted the possibility of future admissions. In doing so, some stated a desire for crisis planning and helping service users feel less nervous about admission by letting them familiarise themselves more comfortably with hospital settings and choosing their own admitting preferences by means of advanced directives. Caregivers expressed a need for support from the mental health services. Many wished to be involved in or consulted on their relative’s care and to receive information regarding their relative’s health and progress. The service user’s right to confidentiality was viewed as a barrier to helping them care for their relative efficiently. A proportion of participants felt that the mental health services were infringing upon their rights as caregivers and humans by purposively adopting a strict adherence to the confidentiality clause and thus preventing families from being involved. Caregivers felt they shouldered great responsibility in return for little guidance, support and protection from their relative’s mental health service and, sometimes, extended family. In the absence of such support, help was sought from external sources such as support groups where they could share their experiences and receive guidance from individuals with similar experiences. Caregivers recounted that their relationship with their relative improved after an extensive period from the admission. Some feared this would be aggravated should the service user become acutely unwell again and refuse treatment. Others felt confident that their relative would confide in them should they feel unwell again.

Societal stigma and not being informed or educated about mental illness were cited as reasons for not seeking help sooner. Caregivers, retrospectively, associated their experiences of their relative’s admissions, hospitalisations and illness with feelings of self-blame for not intervening sooner and regret for how much their relative’s lives differed from their earlier aspirations. Furthermore, families reported a sense of duty or obligation to care for their relative and expressed hopelessness that their relative’s illness and their caregiving situation would never alleviate. In some participants, this was unaided by anger directed to health professionals who failed to apologise for their neglect after years of misdiagnosing their relative’s illness and further distressed by their feelings of shame and guilt for their relative’s illness. Lastly, our sample of participants emphasized a need for early intervention and public education. American families stipulated that raising public awareness and increasing
governmental spending on mental healthcare were key ingredients to improving both service users’ and caregivers’ experiences of admission and treatment.

9.2 Comparison with previous research

Caregivers, in this study and in others’, expressed growing concern for their relative’s wellbeing following the onset of symptoms with many highlighting difficulty accessing mental health treatment or not always knowing who to contact in an emergency (Jankovic et al., 2011). In these cases, mental health services were viewed as responding tardily to caregivers’ requests for help as well as acting reactively rather than proactively towards service users’ health (Jankovic et al., 2011). Although the term ‘burden’, as outlined in our quantitative study, has received substantial criticism for its focus on the negative aspects of caregiving (Szmukler et al., 1996), few caregivers spoke of positive experiences that emerged from their experiences in the qualitative study. Feeling burdened was evident in our sample of caregivers when they spoke of their difficulties in sourcing appropriate help for their relative or when mental health services failed to respond to a perceived emergency (Giacco et al., 2012). Experiencing such stressors may, in turn, cause disruption in other areas of the caregiver’s life resulting in both physical and psychological strain (Schulz & Sherwood, 2008).

Our study supports the notion that caregivers experienced trauma from the onset of their relative’s illness and admission to hospital that was compacted by a perceived sense of obligation and lack of forewarning (Martens & Addington, 2001). Similarly to our study, many caregivers felt relieved by the admission as it provided them with both a sense of respite from their caregiving role and a sense of security that their relative was in a safe location (Jankovic et al., 2011; Jansen et al., 2015). Such an admission initially instilled hope in caregivers who longed for their relative to recover to health during hospitalisation (Jansen et al., 2015). However, upon reflecting on the admission and hospitalisation, caregivers expressed a number of different emotions. Contradictory feelings of guilt, worry, shame, despair and anger were associated with involuntary admission in our sample and in previous
research (Hooley, 2007; Jankovic et al., 2011). Some of these feelings may result from having unmet needs (Szmukler et al., 1996). Caregivers’ anger, for example, may be attributable to their realization that their relative’s illness may be a permanent feature in both their lives despite their efforts to control it (Karp & Tanarugsachock, 2000). Feelings of shame or embarrassment may be linked to unconventional social behaviours that are exhibited publicly and feelings of frustration may be attributable to the service user’s denial or lack of insight into their illness (Karp & Tanarugsachock, 2000). These may be related to perceptions of societal stigma or perceived ability to help the service user or bring about any improvement (Biegel & Schulz, 1999).

As replicated in our sample of caregivers, a reduction in length of inpatient stays affected caregivers negatively (Biegel, 1998; Lauber, Eichenberger, Luginbuhl, Keller, & Rossler, 2003). This was felt acutely by caregivers who recounted that their relative was discharged prior to making a full recovery and without an opportunity for them to provide input into the decision-making process (Jankovic et al., 2011). Previous studies have indicated that this sense of burden lessened in caregivers when the service user’s level of functioning improved (Magliano et al., 2000). Our finding that caregivers’ whose relative did not resume a ‘normal’ routine that included work expressed substantial feelings of burden and distress is partly in line with that of Magliano et al.’s (2000). It is also possible that caregivers who placed their relative’s needs above their own may have developed higher levels of distress (Ostman, Hansson, & Andersson, 2000).

Similarly to earlier research, many of the caregivers in this study revealed sadness and frustration at being unappreciated and uninvolved by the service user or mental health services despite their unrelenting efforts at providing care for their relative (Biegel, Song, & Milligan, 1995; Jansen et al., 2015). This is supported by Karp and Tanarugsachock (2000) who found that caregivers were treated with hostility rather than gratitude by the service user. Hospital admission was linked to family discord where caregivers felt they were treated with hostility by the service user and that the relationship broke down as a consequence of involuntary admission (Magliano et al., 1998). This may be particularly difficult for
caregivers who continue to provide care to a relative who does not recognise or return these feelings. It is perhaps probable for caregivers to question their role when confronted with such challenges.

According to Jankovic et al. (2011), caregivers’ contact with their relative’s mental health service caused distress in and of itself. This was true of the caregivers in this study who felt distressed by needing to ‘push’ the services into providing treatment for their relative. Caregivers’ reports of dismissal from the mental health service attended by their relative are common in family literature. Similarly to our study, dismissal was linked with dissatisfaction with the mental health services for not providing immediate care upon onset of acute illness, for not providing information about their relative’s illness or care and being expected to shoulder the challenges that accompany caring for an individual with a mental illness (Jankovic et al., 2011). Feeling dismissed by mental health services may lead such caregivers may alienate them from the services.

In line with the stress-coping paradigm, the extent to which the service user’s illness affects the caregiver may depend on their psychosocial coping resources. Some of the caregivers who were interviewed in our study reported a lack of family, social and clinical support, which they felt would alleviate their distress. Similarly to previous research, this sample of caregivers expressed difficulty in coping with their relative’s symptoms during an acute illness that limited their daily life (Kuipers, 1993). However, unlike the aforementioned research, this sample of caregivers did not speak of limitations in their social or leisurely routines or working life. As many of the caregivers interviewed had relatives with an enduring mental illness from a young age, it is possible that their routines and appraisals of importance regarding social aspects shifted many years previous to the time of interview and that these changes no longer caused significant distress. As the study primarily addressed caregivers’ experiences of admission, it is likely that when caregivers were asked about aspects they were happy or unhappy with surrounding their relative’s admission, that other factors were viewed as more distressing and may have taken precedence.
9.3 Implications

Burden and unhelpful coping mechanisms are recurrent phenomena that remain unchanged in the absence of family intervention (Magliano et al., 2000). Therefore, it may be helpful for caregivers to avail of psychoeducation that provides them with information on mental illness, evidence-based therapies available as well as teaching them how to improve communication with their relative and cope with challenging (and enduring) situations. As coping strategies have been strongly implicated in caregivers’ perceptions of their experiences, psychological distress and burden, such intervention must focus on helping them shift to less emotion-centred methods of coping. Increased socialization has also received support for acting as an effective intervention in improving an individual’s response to stress thus reducing the incidences of psychological distress (Buchanan, 1995; Magliano et al., 1998). Difficulties acquiring and sharing information regarding the service user’s health was a frequent complaint in caregivers in our study and others (Szmukler et al., 1996). Clinicians face substantial difficulty in balancing caregivers’ wishes to be involved in the service user’s care and the service user’s right to confidentiality. As portrayed by some of the caregivers involved in this study, this failure to confide in caregivers may place caregivers at risk. In attempting to empower service users, we may, simultaneously, be disempowering caregivers.

Following the caregivers’ descriptions of the barriers they experienced in attaining emergency treatment for their relative suggests that training on recognizing and dealing with acute mental illness to emergency medical services, the police force, general practitioners and out-of-hours doctors may be warranted. Accessing involuntary treatment for the service user was fraught with difficulties for caregivers. Providing a separate room for caregivers and service users with a serious mental illness to wait for medical attention as opposed to a waiting room in an accident & emergency department of a general hospital may help lessen both individuals’ anxiety upon entering hospital for treatment.

Caregivers too can play a role in helping their relative be less frightened at admission. Advanced directives where service users can choose their preferences for care may help
assuage service users’ fear by giving them control and choice regarding their admission and treatment. Familiarising the service user and caregiver with the hospital and staff at a time when the service user is well may also be helpful as service users may be more comfortable entering known and trusted surroundings.

As family caregivers are often the principal caregivers in the service user’s life prior to admission and following discharge, mental health services could assist caregivers by asking for their opinions on what they feel may be helpful for the service user’s care and by providing them with a point of contact, such as the service user’s key worker, whom they could contact to refer necessary information onto. It is important for caregivers, however, to also examine their behaviour in helping the service user and evaluate whether they display aspects of criticism, hostility or overinvolvement in their relative’s life that may cause further debilitation.

Caregivers noted a significant disparity in how the service user was treated by staff depending on whether the service user entered a private or state-run clinic. Being able to avail of private insurance was especially influential in caregivers of service users who were admitted in Connecticut who outlined that the quality of care and the length of admission were inferior in public hospitals. Both caregivers asked for mental health services to provide aftercare for their relative that could teach service users how to help themselves and help them re-integrate within their community and eventually secure independent living. This lack of continuity of care after discharge has appeared in other qualitative studies (Shankar & Muthuswamy, 2007).

In light of caregivers’ accounts, it is possible that mental health services are failing to acknowledge the unmet needs of caregivers and neglecting their duty to care for the caregiver, and thus, the service user in the long-term. Mental health services that are under pressure and time constraints to deliver uninterrupted quality care to service users could facilitate sessions in which they impart information onto caregivers who could then ask questions on a face-to-face basis. As caregiver support groups often do not differentiate
caregivers’ varying experiences attributable to their age, how long they have provided care to their relative and the type of relationship they share with their relative (Hatfield, 1997a, 1997b), therapeutic groups where a qualified mental health professional can help support caregivers in their own journey towards personal recovery and recovery as a family.

Finally, although this study focused primarily on the caregiver’s experience of admission and hospitalisation, caregivers’ perspectives consisted of their reflections of the admission obtained after discharge. It is likely that these caregivers experienced multiple hospitalisations and were most likely influenced by events occurring or most relevant to them according to the time of interview. For example, it is likely that caregivers may focus more negatively upon the admission if the caregiver was recently involved in a difficult re-admission. Additionally, it is likely that caregivers may stress their experiences of after care upon discharge if interviewed at such time point.

9.4 Strengths and Weaknesses

The present study comprised of a number of strengths. Firstly, the study included caregivers from two different countries with very different judicial systems for accessing involuntary admission. Caregivers’ experiences of their relative’s illness and admission were, therefore, compared with these differences in mind. Our Irish interviews reached a point whereby no further new data appeared to be offered by caregivers. Unfortunately, this point may not have been reached in interviews conducted in Connecticut with regards to caregivers’ experiences of admission due to time constraints during the internship at Yale University. However, many of the themes pertaining to their experiences of illness, hospitalisation and discharge overlapped with those illustrated by Irish caregivers.

A number of weaknesses were also identified. Our sample of caregivers consisted primarily of mothers. This finding is consistent with previous studies where female parents were the primary participants (Giacco et al., 2012; Magliano et al., 1998; Winefield & Harvey, 1993). Although our findings shed some light into the experiences of caregivers but are, however,
limited by our small sample of participants and our lack of demographic and clinical data regarding the caregivers interviewed and their relatives. Although generalisability is not a focal point of qualitative research, a larger sample that included such data may have given us a further range of caregivers experiences to explore.

Furthermore, participants were recruited by means of advertising within mental health organisations. Those who participated in this study may have been biased due to their self-selection and may not have been representative of all caregivers. Caregivers were also not re-contacted following interview transcription to confirm their views. This did not take place due to time constraints and difficulties in re-contacting our American sample. Finally, reflecting upon the interviews, it became clear to the researcher that although the focal point of the interview was on understanding caregivers’ experiences of the admission, this topic was frequently not what caregivers wished to discuss. It became apparent that caregivers often felt that present circumstances were distressing and that they wished to discuss events happening in their life at the time of the interview. Using thematic analysis allowed us to look at their various experiences relative to both time points and to elaborate on what we felt were recurring themes within the transcripts.

9.5 Future Research & Education

We are presently lacking longitudinal studies that evaluate whether caregivers’ perceptions of their experiences change over time. One study by Karp and Tanarugsachock (2000) has proposed that the emotions experienced by caregivers during their relative’s illness change with a change in obligations. According to their model, caregivers experience considerable confusion at the onset of illness that is alleviated by receiving a medical diagnosis. Such diagnosis provides caregivers with clarity, a sense of hope and optimism that service users will return to health and compassion for their relative who is experiencing acute illness. However, this optimism begins to fade and shifts towards feelings of anger and resentment in caregivers of service users with an enduring mental illness as the prospect of a full return to health is distanced. Those who realize that their best efforts cannot sufficiently control their
relative’s illness may emerge with a sense of acceptance of their relative’s condition and loss for immaterialised aspirations. A portion of these caregivers come to admire and respect their relative for enduring such illness and shift towards helping the service user accomplish as happy a life as possible. The present study may have included caregivers who were at different stages of their family-life cycle that may have accounted for the variety of feelings expressed during their interviews. A longitudinal study, however, may give us a better idea of caregivers’ experiences of the admission, hospitalisation and discharge as they occur.

The National Institute for health and Care Excellence (NICE) guidelines outline a need for caregivers to avail of family interventions, carer-focused education and support programmes from mental health services that train, support and provide caregivers with a helpful toolkit to help caregivers in their role. A study evaluating caregivers’ perceptions of their ability to access such interventions as advocated by the NICE guidelines and their perceptions regarding the quality and delivery of such interventions may help highlight disparities in availability of services to policy makers and may, in turn, help shape and improve the support provided to caregivers within those treatment services.

On a final note, many caregivers voiced that they were unable to identify their relative’s illness at the onset of his or her first acute symptoms. Mental health services must take steps to involve caregivers in devising a way to inform the public about mental illness, how to spot the early warning signs of a (recurring) mental illness and where to go for help. Such a guide must also inform caregivers on how to help prevent a relapse, how to look after their own wellbeing, especially during periods of sustained illness and/or challenging behaviour, and the possible side effects of medication. Finally, educating future generations on how to recognize the symptoms of mental illness prior to the average age of onset of illness may help shorten the duration of an untreated illness.
Chapter Ten

Concluding Remarks

The central tenet of this thesis was to examine the caregiver’s perspective of the service user’s admission to psychiatric hospital. The idea for this thesis emerged from a study, the primary researcher was involved in, that focused on understanding the service user’s perspective of his or her own psychiatric admission. During that study, it became evident, to the researchers involved, that a more nuanced picture of the service user’s admission must include the caregiver’s viewpoint. From there, we then set out to understand the caregiver’s perspective of their relative’s admission. Adopted from this earlier study, this perspective included both an assessment of the caregiver’s perception of coercion, pressures and procedural justice from the admission as well as an examination of how a set of psychological constructs, previously affiliated to psychiatric admission within the caregiver literature, may affect this perspective.

We initially envisaged that this perspective would focus on theoretically-driven, pre-selected constructs present within the literature and measured quantitatively. Some of these constructs were adapted from the service user study, whilst others were borrowed from the caregiver literature where they appeared as key concepts. This, we found, was an especially fruitful and wonderful exercise that allowed us to meet caregivers, hear their stories and try to place ourselves in their shoes for the duration of the study. By means of this quantitative study, we were able to determine the extent to which the caregiver viewed their relative’s admission as coercive, pressured and just, and understand whether these perceptions were linked to the aforementioned theoretical constructs.

However, upon completion of the quantitative study, we realised that many of the experiences caregivers spoke of could not be amply collected by using this method. For this reason, we incorporated a qualitative component that could describe caregivers’ rich and...
unique experiences regarding their relative’s admission and treatment. This qualitative study stemmed from its predecessor. It was based on our primary outcome measure, the Admission Experience Survey, and included questions pertaining to the lead-up to the admission and experiences following discharge that may determine or influence the caregiver’s perspective regarding the admission.

Both studies helped us understand what caregivers may experience when their relative becomes unwell. As with many studies, our study’s weaknesses may have affected what we found or did not find. Some of our findings surprised us whilst others resonated with earlier studies’ findings. Nevertheless, as a whole, our results point to a need for us to support caregivers. Aware of the restrictions affronted by mental health teams, we posit, nonetheless, that a duty of care be extended to caregivers. The availability of such support, unfortunately, is uncertain.
Part III:

REFERENCES
References


Richards, H. M., & Schwartz, L.J. (2002). Ethics of qualitative research: are there special issues for health services research? *Fam. Pract, 19*(2), 135-139.


151


Part IV:

APPENDICES

APPROVALS

Appendix I: Ethical approval from Trinity College Dublin
Appendix II: Ethical approval from St. John of God (provisional)
Appendix III: Ethical approval from St. John of God (full)
Appendix IV: Ethical approval from Galway University Hospital
Appendix V: Ethical approval from Newcastle Hospital
Appendix VI: Ethical approval from Trinity College Dublin (add.)
Appendix VII: Letter of support from Yale School of Medicine
Appendix VIII: National Institutes of Health Certification
Appendix IX: HIPAA Certification
14th March 2012

F.A.O. Veronica Ranieri

School of Psychology Research Ethics Committee

Dear Veronica,

I am pleased to inform you that your application entitled “Caregivers’ perspectives of their relative’s admission” has been approved by the School of Psychology Research Ethics Committee.

It is not routine policy of the Committee to issue duplicate or replacement letters confirming ethical approval. It is therefore the responsibility of the applicant to keep the approval letter safe.

Yours sincerely,

[Signature]

Dr. Tim Trimble
Chair
School of Psychology Research Ethics Committee
24th October 2011

Ms Veronica Ranieri
24 William Bligh
The Gasworks
Barrow Street
Dublin 4

Dear Veronica,

Re Proposal: “Caregivers’ Perspectives of Relative’s Admission”

Thank you for attending the meeting of the Provincial Ethics Committee on 18th
October and presenting the above proposal.

The Provincial Ethics Committee is happy to approve your proposal pending receipt
of the following amendments:

➢ Confirmation of Kevin Madigan as the person who supplies the list of
consenting subjects to you and who, as a clinician, approaches these subjects
initially.
➢ Letter of Information: Source Information leaflet to be included with letter of
information to Caregivers, detailing your status as a SOURCE member and
Service user.

Please forward your amendments for the attention of Jackie Hall at the address above.
Please note there is no need to return the entire application again. Only the
amendments, clearly highlighted are required. Following receipt of these
amendments the Provincial Ethics Committee will be in a position to formally
approve this study. If you have any further queries please do not hesitate to contact
Jackie Hall on 01 277 1500 Ext 1694.

Kind regards

Yours sincerely

Melanie Gallagher
Acting Chair
Provincial Ethics Committee
19th December 2011

Ms Veronica Ranieri
24 William Bligh
The Gasworks
Barrow Street
Dublin 4

Dear Veronica,

Re Proposal: ID 465 “Caregivers’ Perspectives of Relative’s Admission”

Thank you for the above research proposal submitted to the Provincial Ethics Committee.

The Provincial Ethics Committee have pleasure in formally approving the above research proposal. Commencement of the project is subject to your collaborator Kevin Madigan’s confirmation that good research practice is in place to support the proposed project, as per Aine Kelly’s letter to Kevin Madigan dated 19th December, 2011.

Kind regards

Yours sincerely

__________________________
Jane McEvoy
Chair
Provincial Ethics Committee

c.c. Mr Pat Conroy, Director, Cluain Mhuire Service
Mr Brian O’Donoghue, Sponsor, Cluain Mhuire Service
Dr Larkin Feeney, Sponsor, Cluain Mhuire Service
Mr Shane Hill, Sponsor, Cluain Mhuire Service

Hospitaller House, Stillorgan, County Dublin, Ireland. | Tel: 01 2771500 | Fax: 01 2783024 | Email: programmes@sjog.ie | www.sjog.ie
Clinical Research Ethics Committee  
Main Administration Building  
Merlin Park Hospital  
Galway.  

14th March, 2013.

Dr. Brian Hallahan  
Consultant Psychiatrist  
Roscommon County Hospital & Honorary Senior Clinical Lecturer  
Department of Psychiatry  
Clinical Science Institute  
National University of Ireland Galway.

Ref: C.A. 524 - A prospective evaluation of the operation and effects of the Mental Health Act 2001 from the viewpoints of service users and health professionals

Amendment 1 – March 2013

Dear Dr. Hallahan,

I have considered the above amendment, and I wish to grant Chairman’s approval to proceed.

Yours sincerely,

Dr. Shaun T. O’Keeffe  
Chairman Clinical Research Ethics Committee.
To Ms Veronica Ranieri  
School of Psychology    
Aras an Phiarsaigh  
TCD  
Dublin 1

20th November 2012

Research project. Caregivers’ perspectives of their relative’s Admission

Dear Ms Ranieri

Further to a recent meeting of the Newcastle Hospital Ethics Committee. I am pleased to inform you that your proposed research project was approved.

We would recommend that you would number the pages of the study proposal (eg 1 of 18) to assist in the photocopy process and in the event that the pages become separated.

We would be pleased to receive a copy of your final results/report in due course.

Kindly contact me on 0863400500 if you wish to discuss case finding at Arklow Psychiatric OPD.

Yours Sincerely,

[Signature]

Marjorie Stokes MB MPH MRC Psych MCRN 09126

Coordinator Ethics Committee
F.A.O. Veronica Ranieri

School of Psychology Research Ethics Committee

17 October 2013

Dear Veronica,

The School of Psychology Research Ethics Committee has reviewed your application entitled “Caregivers’ Perspective of their Relative’s Admission (Addendum)”, and I am pleased to inform you that it was approved following amendments made.

Yours sincerely,

[Signature]

Richard Carson
Chair,
School of Psychology Research Ethics Committee

SCHOOL OF PSYCHOLOGY
Arás an Phiarsaigh
Trinity College
Dublin 2
September 24, 2014

School of Psychology
Aras an Phiarsaigh
Trinity College Dublin
College Green, Dublin
Ireland

To Whom it may Concern:

This letter is being provided to attest to the fact that Yale IRB approval was not required for Ms. Ranieri to conduct telephone and Skype interviews with members of the Connecticut Chapter of the National Alliance on Mental Illness. Upon consultation with the Yale IRB office, it was determined that the IRB approval Ms. Ranieri received from her home institution was considered appropriate to address the human subjects issues involved in conducting these interviews with members of a community-based organization that has no formal relationship to the University. As she had no formal position at Yale, the University did not think it appropriate to issue its own IRB approval. Should you have any additional questions about this matter, please feel free to contact me at the addresses above.

Thank you for your attention to this matter.

Sincerely,

Larry Davidson, Ph.D.
Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that Veronica Ranieri successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 09/27/2013

Certification Number: 1283917
Researcher’s Guide to HIPAA

Researcher Certification

Compliance with HIPAA in Research Projects

I understand that patient records including demographic, biographic, insurance, financial, and clinical information are confidential and are subject to the requirements of HIPAA. In the course of employment or association with a Yale University research project, this information may be required and consequently accessed from file folders, computer display screens, and computer printers. I understand that I should only access that information which I need to perform my research related duties.

Release of this confidential information, either written or verbal, except as required in the performance of research, is a critical violation of research conduct. As such, it may be considered reason for immediate termination and could result in civil and criminal penalties under the Health Insurance Portability and Accountability Act of 1996 as amended by the HITECH Act of 2009.

I have read and understand the Researcher’s Guide to HIPAA and agree to the above statements.

[Signature] 25/09/13

Please print or type name

VERONICA PANIERI

Home Institution

YALE (& TRINITY COLLEGE DUBLIN)

Research Project Title or HIC Protocol Number

CAREGIVER'S PERSPECTIVES
OF THEIR RELATIVE'S ADMISSION

Researcher PI

Yale PI

Forward to:
HIPAA Privacy Office
2 Whitney Ave, Suite 204
P.O. Box 208252
New Haven, CT 06520-8252
Fax: 203-432-4033

Version 05/2010
Part V:

SERVICE USER PARTICIPATION - QUANTITATIVE

Appendix X: Service User information sheet for own participation
Appendix XI: Service User letter of consent for own participation
Appendix XII: Service User information sheet for caregiver participation
Appendix XIII: Service User letter of consent for caregiver participation
Appendix XIV: Admission details
Appendix XV: Global Assessment of Functioning Scale
Appendix XVI: MacArthur Admission Experience Survey
Appendix XVII: Service Users’ Perspectives of Admission Study Article
Letter of Information

Dear ________

A study is being undertaken in St John of God Hospital entitled “Service Users’ Perspectives towards their admission” by the SOURCE Committee and Medical staff in St John of God Hospital. The Study is being undertaken by Dr Ciaran Crumney, Dr Brian O’Donoghue, Veronica Ranieri, Kevin Madigan and Dr John Lyne.

The purpose of the study is to investigate service users views and attitudes towards their admission to hospital. The study will help get a clearer picture of the experience of being admitted to hospital and we hope it will help shape future clinical practice for the better.

If you wish to be involved in the study it would require you to be interviewed a few days prior to discharge and then one year later. The study will be completed one year following your discharge. Follow-up contact will be made by a phone call or letter to your home.

Data Collection, analysis and storage will be inline and accordance with the Data Protection Act Best practices in Scientific Research.

The information obtained will be confidential and the interviewer will not be a member of your treating team. The answers you give will not be given back to your doctors or anyone involved in your care. Whether you wish to participate in the study or wish to decline the offer will have no impact on your usual treatment and your decision will not have any negative impact on the care or treatment you receive. You have the freedom to choose to participate or not.

The collective results of the study may be published or presented at academic meetings. However no individual will be identified.

I would like to thank you for considering participating in the study and if you have any questions regarding the Study please do not hesitate to contact me at 01-2791700.

Yours Sincerely,

Dr Brian O’Donoghue
Letter of Consent

Date:

Title: Service Users' Perspectives towards their admission

Name of Principal Researcher: Dr Brian O'Donoghue
Contact Details: 01-2791700

I have spoken with the researcher and have read the Information sheet and I have had the opportunity to ask questions about the study.

I understand that it will be required for me to answer a questionnaire regarding my admission prior to discharge and one year later. I give my consent for information to be obtained from my clinical case notes for this study.

I understand that the things I say will be confidential and that I will not be recognised, as my name will not be used.

I understand that I am not required to be involved in the study and that I can stop answering questions at any time and this will have no impact on the treatment and services I receive. I understand that I can request that my information not to be used in the study at any time.

I understand and give my consent to be contacted by telephone or letter to my home 12 months following initial contact.

I understand that the results of this study may be published in a report, article or book and I will not be identified in any published material.

I understand that the data will be kept and destroyed in accordance with the data protection act.

I agree to Participate in the Study

Name: [Signature] Date

Witness: [Signature] Date
Letter of Information

Dear ________________.

We are very grateful for you having taken part in the project entitled ‘Service Users’ Perspectives towards their Admission’. We are also meeting with service user’s family members or partners and hearing about their experiences and any recommendations that they may have to change the service. Ms. Veronica Ranieri will be undertaking these interviews.

We would only meet with your family members or partner with your agreement and it is optional for them to take part. We would like to highlight, that participation in this study is completely voluntary and whether you take part of not, it will not affect your treatment and care that you already receive. We will not disclose any of your confidential information to your family member or partner.

We would hope that after meeting with family members and partners, we will have a number of suggestions to help improve the mental health services. Therefore, the findings from the project may published or presented at a conference, however, you and your carer will not be identifiable or recognizable from this.

The data from the completed questionnaires will be stored in accordance with the Data Protection Act Best Practices in Scientific Research.

If you are agreeable with your family member or partner being contacted, we would be grateful if you could please sign the attached consent form. If you have any questions regarding the study, please do not hesitate to contact me at 01-2791700.

Yours Sincerely,

[Signature]

Dr. Brian O’Donoghue MRCPsych
Consent Form

Title: Service Users Perspectives of their Admission – Family/ Partner Interview

I have met with the researchers and I have been provided with the information sheet on the project which involves meeting with family members or partners. I understand the nature and purpose of this study and I have had the opportunity to ask questions.

I am willing to consent for my family member/ partner to be invited to take part in this project.

Name of family member/ Partner: ____________________________

Contact Number: _______________________________________

Signed: ____________________________  Date: _____________

I also consent to the researchers contacting me in four years’ time to invite me to participate in a follow-up interview.

Signed: ____________________________  Date: _____________

Witness: ____________________________  Date: _____________
<table>
<thead>
<tr>
<th><strong>Readmission Details (if applicable)</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Re-Admission</td>
<td></td>
</tr>
<tr>
<td>Date of discharge</td>
<td></td>
</tr>
<tr>
<td>Voluntary/ Involuntary</td>
<td></td>
</tr>
<tr>
<td>If Involuntary - Commenced by:</td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Authorised Officer</td>
<td></td>
</tr>
<tr>
<td>Gardai</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td></td>
</tr>
<tr>
<td>Date of Invol order</td>
<td></td>
</tr>
<tr>
<td>Date of Invol order revoked</td>
<td></td>
</tr>
<tr>
<td>No of Tribunals</td>
<td></td>
</tr>
<tr>
<td>Date of Tribunals</td>
<td></td>
</tr>
<tr>
<td>Result of Last Tribunal</td>
<td></td>
</tr>
<tr>
<td>Renewed</td>
<td></td>
</tr>
<tr>
<td>Revoked</td>
<td></td>
</tr>
<tr>
<td>Risk to self/ others</td>
<td></td>
</tr>
<tr>
<td>Deterioration of mental state</td>
<td></td>
</tr>
<tr>
<td>Form 6</td>
<td></td>
</tr>
<tr>
<td>Form 13 (vol then detained)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Coercion</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Brought to Hospital by:</td>
<td></td>
</tr>
<tr>
<td>Gardai</td>
<td></td>
</tr>
<tr>
<td>Assisted Admission team</td>
<td></td>
</tr>
<tr>
<td>Restraint</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
</tr>
<tr>
<td>Length of time</td>
<td></td>
</tr>
<tr>
<td>Number of incidents of restraint:</td>
<td></td>
</tr>
<tr>
<td>Seclusion</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
</tr>
<tr>
<td>Length of time</td>
<td></td>
</tr>
<tr>
<td>Number of incidents of seclusions:</td>
<td></td>
</tr>
</tbody>
</table>

| **Date:** |  |
| Medication without consent | Yes | No |
| Date: |  |
| Medication: |  |
| Dose: |  |
| Reasons: |  |
| Number of incidents of medication w/o consent |  |

| Brought to hospital with involuntary admission forms completed but agreed to stay voluntary | Yes | No |
| Treated on Locked, secure ward: | Yes | No |
SCID-I/P (for DSM-IV-TR)  (NOV 2002)  Summary Score Sheet bx

DSM-IV Axis V: Global Assessment of Functioning Scale

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

CODE (Note: Use intermediate codes when appropriate, e.g., 45, 68, 72).

100 Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his many positive qualities. No symptoms.

91

90 Absent or minimal symptoms (e.g., mild anxiety before an exam); good functioning in all areas, interested and involved in a wide range of activities, socially effective, generally satisfied with life, no more than everyday problems or concerns (e.g., an occasional argument with family members).

81

80 If symptoms are present, they are transient and expectable reactions to psychosocial stressors (e.g., difficulty concentrating after family argument); no more than slight impairment in social, occupational, or school functioning (e.g., temporarily falling behind in school work).

71

70 Some mild symptoms (e.g., depressed mood and mild insomnia) OR some difficulty in social, occupational, or school functioning (e.g., occasional truancy, or theft within the household), but generally functioning pretty well, has some meaningful interpersonal relationships.

61

60 Moderate symptoms (e.g., flat affect and circumstantial speech, occasional panic attacks) OR moderate difficulty in social, occupational, or school functioning (e.g., few friends, conflicts with peers or coworkers).

51

50 Serious symptoms (e.g., suicidal ideation, severe obsessional rituals, frequent shoplifting) OR any serious impairment in social, occupational, or school functioning (e.g., no friends, unable to keep a job).

41

40 Some impairment in reality testing or communication (e.g., speech is at times illogical, obscure, or irrelevant) OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).

31

30 Behavior is considerably influenced by delusions or hallucinations OR serious impairment in communication or judgment (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) OR inability to function in almost all areas (e.g., stays in bed all day; no job, home, or friends).

21

20 Some danger of hurting self or others (e.g., suicide attempts without clear expectation of death, frequently violent, manic excitement) OR occasionally fails to maintain minimal personal hygiene (e.g., smears feces) OR gross impairment in communication (e.g., largely incoherent or mute).

11

10 Persistent danger of severely hurting self or others (e.g., recurrent violence) OR persistent inability to maintain minimal personal hygiene OR serious suicidal act with clear expectation of death.

0 Inadequate information.
Perceived Coercion

1. I had more influence than anyone else on whether I came into hospital
2. I had a lot of control over whether I went into the hospital
3. I chose to come into the hospital
4. I felt free to do what I wanted about coming into the hospital
5. It was my idea to come into the hospital

Perceived Pressures

1. Did anyone try to talk you into going to hospital or being admitted?
2. Did anyone offer or promise you anything?
3. Did anyone threaten you?
4. Did anyone force you?

Procedural Justice
(these four questions are to be asked regarding each person involved with the decision)

1. To what extent did he/she do what he/she did out of concern? (very much, mostly, a little, not at all)
2. How much respect did he/she treat you with? (very, some, a little, none)
3. How seriously did he/she consider what you had to say (very, some, a little, none)
4. How fairly did he/she treat you? (very fair, mostly fair, mostly unfair, very unfair)
Perception towards Admission

1. How do you reflect on the necessity of your admission
   Necessary     Unnecessary     DK

2. Overall, was your admission beneficial
   Beneficial     Unbeneficial     DK

3. Do you think that your admission to hospital was justified:
   Justified     Unjustified     DK

Impact on Relationships

1. Did your admission have any effect on the relationship with your family
   Yes          No          DK

2. Did your admission have any effect on the therapeutic relationship
   with your consultant psychiatrist?
   Yes          No          DK

3. Did your admission have any effect on your employment
   Yes          No          DK

Please explain__________________________________________________________
Service Users' Perceptions About Their Hospital Admission Elicited by Service User—Researchers or by Clinicians

Brian O'Donoghue, M.Sc., M.R.C.Psych.
Eric Roche, M.B., M.R.C.Psych.
Veronica F. Ranieri, M.A., M.Sc.
Ciaran Crummey, Ph.D.
Johanna Murray, M.B.

Damian G. Smith, M.B., M.R.C.Psych.
Kieran O'Loughlin, M.B., M.R.C.Psych.
John P. Lyne, M.Sc., M.R.C.Psych.
Kevin Madigan, R.P.N., M.Sc.
Larkin Feeney, M.Sc., M.R.C.Psych.

Objective: Service users may express positive, ambivalent, or negative views of their hospital admission. The objective of this study was to determine whether the background of the interviewer—service user—researcher or clinician— influences the information elicited. The primary outcome was the level of perceived coercion on admission, and secondary outcomes were perceived pressures on admission, procedural justice, perceived necessity for admission, satisfaction with services, and willingness to consent to participation in the study.

Methods: Participants voluntarily and involuntarily admitted to three hospitals in Ireland were randomly allocated to be interviewed at hospital discharge by either a service user—researcher or a clinician. Interviewers used the MacArthur Admission Experience Survey and the Client Satisfaction Questionnaire.

Results: A total of 161 participants were interviewed. No differences by interviewer status or by admission status (involuntary or voluntary) were found in levels of perceived coercion, perceived pressures, procedural justice, perceived necessity, or satisfaction with services. Service users were more likely to decline to participate if their consent was sought by a service user—researcher (24% versus 8%, p=0.003).

Conclusions: Most interviewees gave positive accounts of their admission regardless of interviewer status. The findings indicate that clinicians and researchers can be more confident that service users' positive accounts of admissions are not attributable to a response bias. Researchers can also feel more confident in directly comparing the results of studies undertaken by clinicians and by service user—researchers. (Psychiatric Services in Advance, January 15, 2013; doi: 10.1176/aps.001912012)

Both voluntarily and involuntarily admitted service users report high levels of perceived coercion during the admission process and over the course of their admission (1,2). Our understanding of how individuals view their involuntary admission to a hospital and the use of coercive measures is growing. Studies have shown that between 39% and 72% of service users report that their involuntary admission was necessary (3,4). Service users express conflicting views of their involuntary admission, with some describing it as a positive experience or a "necessary emergency break" and others as a negative "unnecessary overreaction"; others are ambivalent or describe it as a "practice in need of improvement" (5–7). Service users find the use of physical coercion dehumanizing. It has proved difficult to predict who is more likely to experience physical coercion.

The study of service user perspectives is complex, and there is evidence that the background of the individual who formulates and asks the questions can influence the information elicited. A systematic review of service users' perspectives on electroconvulsive therapy found that when service users led the investigation, lower rates of perceived benefit were reported than in studies that were led by clinician—researchers (8). It has been noted that "coercion is in the eye of the
beholder” and that the background of the researcher may bias information provided to him or her about perceived coercion (9). In contrast, other studies have found no difference in the level of perceived coercion, discrimination, or satisfaction with services reported by service users when study interviews are conducted by service user–researchers or by clinician-researchers or staff members (10–12). In one study, service users provided more negative responses to service user–researchers; however, the study found no difference in overall satisfaction with services (9).

We aimed to determine whether service users would provide different accounts of their perception of coercion experienced on admission when interviews were conducted by service user–researchers or by clinicians. This study had three unique aspects: it was a randomized study, the comparison was between service user–researchers and clinicians, and we included both voluntarily and involuntarily admitted service users. We also sought to determine whether there was a difference in the levels of procedural justice, perceived pressures, satisfaction with services, and the proportion of individuals consenting to participate in the study when interviews were conducted by service user–researchers or by clinicians.

Methods

Setting

This study was conducted in three hospitals: St. Vincent’s University Hospital, which is a general hospital with a psychiatric ward; Newcastle Hospital, and St. John of God Hospital. These three hospitals receive admissions from three community mental health services in Ireland: Dublin South East mental health service and the Newcastle Mental Health Services in County Wicklow and the Chain Mhúire Mental Health Service in County Dublin. These services cover a combined catchment area population of approximately 390,000. In addition to treating service users from the local catchment area, St. John of God Hospital is an independent psychiatric hospital and receives referrals on a national basis.

We included service users who were admitted privately to St. John of God Hospital.

Participants

All individuals age 18 years and older who were involuntarily admitted to St. John of God Hospital between May 1, 2010, and June 30, 2011, St. Vincent’s University Hospital between August 1, 2010, and June 30, 2011, and Newcastle Hospital between November 1, 2010, and June 30, 2011, were eligible for the study. In order to have a comparable number of voluntarily admitted participants, the next voluntarily admitted service user after each involuntary admission was selected. We also included individuals who were admitted voluntarily but were subsequently detained involuntarily during the admission. According to the Irish Mental Health Act of 2001, individuals with a sole diagnosis of a personality disorder or substance misuse cannot be admitted involuntarily. Therefore, to have comparable samples, we excluded voluntarily admitted service users with either a sole diagnosis of a personality disorder or substance misuse. We also excluded individuals with dementia and intellectual disabilities; those with a first episode of psychosis were excluded because they were involved in another study protocol.

Ethics approval

Written informed consent was obtained from all study participants, and ethics approval was granted at each of the three study centers. We did not offer compensation for participation in the interviews before discharge. We were not granted permission to obtain information about individuals who declined to participate in the study, and therefore we could not compare those who participated with those who declined.

Study design

Participants were randomly assigned to an interview with a service user–researcher or a clinician. Participants were interviewed once a discharge date was set, and interviews occurred in the days before discharge from the hospital. Each participant had a second interview with a clinician before discharge to confirm the diagnosis and measure the severity of symptoms. Participants were not blind to their randomization, because it was an important aspect of the study for participants to know that they were being interviewed by a service user–researcher or a clinician. All service user–researchers informed potential participants that they were a service user–researcher, and all clinicians informed them that they were a doctor or nurse. We did not accommodate requests by potential participants to be interviewed by the other type of interviewer. The interviewing clinician was not a member of the participant’s treatment team. Service user–researchers were involved in all stages of the study design, implementation, and dissemination of results.

To randomly assign participants, a list of the numbers 1 and 2 was generated in random sequence by a Web site (www.random.org); I indicated a service user–researcher and 2 indicated a clinician. This list was generated and kept by an individual who was independent of the study and based in a separate building. The list was concealed from both the researchers and principal investigator.

We used postrandomization consent (Zelen’s design [13]) because the delivery of consent is part of the difference between interviews conducted by service users and by clinicians. Had a service user–researcher or clinician elicited consent before randomization, this may have introduced bias because individuals may have refused consent if asked by a clinician but not by a service user–researcher, or vice versa. This procedure also allowed us to test a secondary outcome—that is, whether participation differed depending on whether consent was sought by a service user–researcher or a clinician.

Informed consent

Once a discharge date had been set, potential participants were informed by nursing staff on the ward that there was a researcher who would like to meet with them about a study. At this point, the potential participant was not informed whether the researcher was a service user–researcher or a clinician. If the potential participant
agreed, a time was arranged for the meeting. Potential participants were provided with oral and written information about the study and were given an opportunity to ask questions and decide whether they wished to participate. There was no time constraint within which potential participants had to decide. Participants could withdraw consent at any stage, which was clearly stated in the letter of information and the consent form.

Instruments
We used the MacArthur Admission Experience Survey (MacArthur AES) to determine the level of perceived coercion, perceived pressures, and procedural justice experienced by an individual on admission to the hospital (14). The primary outcome was level of perceived coercion, which is measured on a scale from 0 to 5, with higher scores indicating a higher level. The level of perceived coercion is obtained from five statements related to the individual’s experience of being admitted to the hospital. The five statements are: “I had more influence than anyone else on whether I entered hospital,” “I had a lot of control over whether I went into hospital,” “I chose to come into hospital,” “I felt free to do what I wanted about coming into hospital,” and “It was my idea to come into hospital.” Answers of “true” are scored 0 and answers of “false” are scored 1. The level of perceived pressures is assessed with four yes-no questions and scored from 0 to 4, with higher scores indicating a higher level. Procedural justice reflects a person’s belief that others are acting out of genuine concern for him or her and that the person is being listened to and being treated respectfully and fairly. This is measured on a scale from 1 to 4, with higher scores indicating a lower level of experienced procedural justice (the person perceives that he or she was less fairly treated) (15).

To evaluate the perceived necessity of the admission, participants were asked, “Do you think it was necessary for you to have been admitted [involuntarily or voluntarily—depending on legal status] to hospital?” We accepted “yes,” “no,” or “don’t know” as answers.

We used the Client Satisfaction Questionnaire (CSQ-8), a self-report, eight-item instrument, to measure satisfaction with services received (16). The CSQ-8 uses a 4-point Likert scale (range 1–4), and a total score (range 8–32) is calculated from summing the scores on the eight items. There is no reliable or valid tool to assess whether an individual perceives the hospital admission to have been necessary. Therefore, we asked a closed question about whether the individual perceived the admission to have been necessary or unnecessary.

Before the start of the project, SOURCE had affiliations with only one of the hospitals involved in the study—St. John of God Hospital. To our knowledge, research involving service user–researchers had not been conducted at the other two hospitals before this project. None of the hospitals employed service user-researchers in professional roles before the start of this project.

Interrater reliability
All interviewers underwent training in the MacArthur AES before the study. Interrater reliability was obtained for all service user–researchers and clinician researchers via interviews with eight inpatients. We developed videos with actors for any interviewers who joined the study after the start date and for retraining. The interrater reliability (kappa) at baseline ranged from .77 to 1.00 for the perceived coercion component, from .77 to 1.00 for perceived pressures, and from .66 to 1.00 for procedural justice.

Statistical analysis
Data were entered into a MS Access database and exported to PASW, version 18, for analysis. For the primary outcome, our a priori power calculation indicated that 102 participants (51 in each arm) were required to detect a difference of 1 in the perceived coercion scale of the MacArthur AES (measured 0–5) with 90% power at the 5% significance level. The null hypothesis states that there is no difference in the information elicited from interviews conducted by service user–researchers and by clinicians. We used chi square tests to determine associations for dichotomous variables and t tests to compare means on continuous variables between the two groups. The Mann–Whitney test was used to determine differences in nonparametric data.

Ideally, the randomization should have controlled for known and unknown confounders between the groups, and the characteristics in both groups should have been similar. However, differences between the groups were noted; individuals interviewed by service user–researchers were younger and more likely to be male and to have more depressive
symptoms. These differences may have occurred by chance or as a result of the method of postrandomization consent. To control for these factors, we used analysis of covariance (ANCOVA) for the MacArthur AES and CSQ-S because the dependent variable was quantitative and there was a combination of qualitative and quantitative explanatory variables. When depressive symptoms were added to the ANCOVA model in which perceived coercion was the dependent variable, a test indicated that the data violated the assumption of equality of error variation. Therefore, for perceived coercion, depressive symptoms were examined separately as a potential confounder and as a dichotomous variable (absent or mild versus moderate or severe depressive symptoms). We used binary logistic regression analysis to control for age, gender, and depressive symptoms for the secondary outcome of the perceived necessity of the admission. [Tables presenting the results of the ANCOVA analysis and the binary logistic regression are available online as a data supplement to this article.]

**Results**

*Description of the sample*

A total of 231 service users were eligible for study participation, of whom 70% (N=161) were interviewed. [A flowchart showing study recruitment and reasons for nonparticipation is included in the online data supplement.] Most of those who were not interviewed were discharged before randomization or before they were able to provide consent (N=23), or they declined to participate (N=31). Of the 161 participants, 48% (N=77) were interviewed by service user–researchers, and 52% (N=84) by clinicians. Those interviewed by service user–researchers were more likely to be male, to be younger, and to have more severe depressive symptoms. However, in terms of legal status, diagnosis, clinical characteristics, and the use of coercion, the groups were similar (Table 1). For the 161 patients in the full sample, the median duration of admission was 37 days (interquartile range 19–58 days).

**Primary outcome: perceived coercion**

Table 2 summarizes information elicited during the interviews by the service user–researchers and the clinicians. No differences were found by interviewer status in the reported level of perceived coercion on admission, either for individuals who were involuntarily admitted or for those who were voluntarily admitted. The findings were the same when the analysis controlled for age, gender, and depressive symptoms.

**Secondary outcomes**

No differences were found by interviewer status in the levels of procedural justice, perceived pressures experienced on admission, and satisfaction with services, either for individuals who were involuntarily admitted or for those who were voluntarily admitted. The findings were the same when the analyses controlled for age, gender, and depressive symptoms.

Among the 161 service users, 118 (73%) viewed their admission to the hospital as necessary. No differences were found by interviewer status. Five (3%) individuals reported that they did not know whether their admission had been necessary, and three (2%) did not provide an answer. Of the 75 service users admitted involuntarily, 54% (N=42) viewed their admission as necessary, and no difference was found by interviewer status. Of the 83 service users admitted voluntarily, 92% (N=76) viewed their admission as necessary, and no difference was found by interviewer status. Results were the same when the analyses controlled for age, gender, and depressive symptoms.

Service users were more likely to decline to participate in the study when consent was sought by a service user–researcher compared with a clinician (24% versus 8%, χ²=9.1, df=1, p=.003). Similarly, the decline rates were higher for service user–researchers when consent was sought from involuntarily admitted service users (31% versus 14%, χ²=3.8, df=1, p=.05) and those who were voluntarily admitted (14% versus 2%, χ²=4.65, df=1, p=.05).

**Discussion and conclusions**

*Summary of findings*

This study found no differences in the information elicited from service users about the level of perceived coercion, perceived pressures on admission, procedural justice, satisfaction with services, and perceived necessity of the admission when the interviews were conducted by service user–researchers or by clinician–researchers. Eligible individuals were less likely to consent to participate in the study if consent was sought by a service user–researcher.

**Context**

The results are consistent with those of Rose and colleagues (10), who found no difference in service users' reports of perceived coercion on admission in interviews conducted by three types of interviewers—service user–researchers who did or did not disclose their service user status and researchers who were not service users. Rose and colleagues sought to determine whether under certain conditions (status disclosed or not disclosed) service user–researchers would obtain differing reports, and the study reported here built on those findings by showing that service users' reports did not differ when interviews were conducted by service user–researchers or by clinicians—a finding that was consistent for both voluntarily and involuntarily admitted service users.

This study found that 59% of service users viewed their involuntary admission as necessary. For involuntarily admitted service users, studies have reported a range of proportions—from 34% in the United Kingdom to 72% in Ireland (2,7). In this study, we interviewed individuals before discharge, which may explain the more positive views; the interviews in the large study in the United Kingdom were conducted on admission. Individuals' views about their involuntary admission have been shown to change over time (22,23).

**Implications**

A unique aspect of this study is that the information elicited by service user–researchers was compared with
Table 1

Characteristics of 161 service users interviewed before hospital discharge by service user–researchers or by clinicians

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (N=161)</th>
<th>Service user–researcher (N=77)</th>
<th>Clinician (N=84)</th>
<th>Test statistic</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>86</td>
<td>53</td>
<td>48</td>
<td>62</td>
<td>38</td>
<td>45</td>
</tr>
<tr>
<td>Female</td>
<td>75</td>
<td>47</td>
<td>29</td>
<td>38</td>
<td>46</td>
<td>55</td>
</tr>
<tr>
<td>Age (M±SD years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>43±14</td>
<td></td>
<td>41±13</td>
<td></td>
<td>45±14</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>40±12</td>
<td></td>
<td>38±11</td>
<td></td>
<td>42±13</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>47±15</td>
<td></td>
<td>45±16</td>
<td></td>
<td>48±14</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>39</td>
<td>24</td>
<td>16</td>
<td>21</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Unmarried</td>
<td>101</td>
<td>63</td>
<td>53</td>
<td>69</td>
<td>48</td>
<td>57</td>
</tr>
<tr>
<td>Separated, divorced, or widowed</td>
<td>21</td>
<td>13</td>
<td>8</td>
<td>10</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychotic disorder</td>
<td>75</td>
<td>47</td>
<td>33</td>
<td>43</td>
<td>42</td>
<td>50</td>
</tr>
<tr>
<td>Anxiety or an affective disorder</td>
<td>86</td>
<td>53</td>
<td>44</td>
<td>57</td>
<td>42</td>
<td>50</td>
</tr>
<tr>
<td>Comorbid diagnosis</td>
<td>24</td>
<td>15</td>
<td>12</td>
<td>16</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>Alcohol, harmful use or dependence</td>
<td>31</td>
<td>20</td>
<td>13</td>
<td>17</td>
<td>18</td>
<td>21</td>
</tr>
<tr>
<td>Admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Involuntary</td>
<td>78</td>
<td>48</td>
<td>41</td>
<td>53</td>
<td>37</td>
<td>44</td>
</tr>
<tr>
<td>First</td>
<td>22</td>
<td>14</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Median length (days)</td>
<td>37</td>
<td></td>
<td>35</td>
<td></td>
<td>39</td>
<td></td>
</tr>
<tr>
<td>Restraint used</td>
<td>26</td>
<td>17</td>
<td>16</td>
<td>22</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Seclusion used</td>
<td>21</td>
<td>14</td>
<td>12</td>
<td>16</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Medication without consent</td>
<td>20</td>
<td>13</td>
<td>10</td>
<td>14</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Any coercive measure</td>
<td>33</td>
<td>21</td>
<td>17</td>
<td>22</td>
<td>16</td>
<td>19</td>
</tr>
<tr>
<td>Measure (M±SD score)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GAFb</td>
<td>40±13</td>
<td></td>
<td>40±14</td>
<td></td>
<td>40±12</td>
<td></td>
</tr>
<tr>
<td>Insightc</td>
<td>9.1±3.3</td>
<td></td>
<td>9.1±3.1</td>
<td></td>
<td>9.0±3.5</td>
<td></td>
</tr>
<tr>
<td>Positive symptomsd</td>
<td>7.6±4.1</td>
<td></td>
<td>7.3±4.0</td>
<td></td>
<td>7.8±4.2</td>
<td></td>
</tr>
<tr>
<td>Negative symptomsε</td>
<td>5.3±4.9</td>
<td></td>
<td>6.1±5.1</td>
<td></td>
<td>4.6±4.7</td>
<td></td>
</tr>
<tr>
<td>Depressive symptomsf</td>
<td>17.3±13.7</td>
<td></td>
<td>20±13.4</td>
<td></td>
<td>14.6±13.4</td>
<td></td>
</tr>
</tbody>
</table>

a Data on use of restraint available for 152 participants; use of seclusion, 151 participants; use of medication without consent, 149 participants.
b Global Assessment of Functioning. Possible scores range from 0 to 100, with higher scores indicating better interviewer-rated global functioning.
c Measured with the Birdwood Insight Scale. Possible scores range from 0 to 12, with higher scores indicating good insight.
d Measured with the Scale for the Assessment of Positive Symptoms only for participants with a diagnosis of a psychotic disorder (N=75). Interviewer-rated possible scores range from 0 to 20, with higher scores indicating more severe positive psychotic symptoms.
e Measured with the Scale for the Assessment of Negative Symptoms only for participants with a diagnosis of a psychotic disorder (N=75). Interviewer-rated possible scores range from 0 to 25, with higher scores indicating more severe negative symptoms.
f Measured with the 21-item, self-report Beck Depression Inventory. Possible scores range from 0 to 63, with higher scores indicating more severe depressive symptoms.

Information elicited by clinicians, and not simply with information elicited by researchers who were not service users. This finding has clinical implications in light of previous findings indicating that most service users have positive views of their involuntary admission after they are discharged (4). Some clinicians may be concerned that a retrospective positive description of a practice that deprived an individual of his or her civil liberties might result from response bias (7). However, if we assume that service users provide a reliable account of their admission to service user–researchers, then clinicians can have confidence in positive accounts provided to other types of interviewers. However, it must be noted that the study was designed to detect a difference in information elicited from interviews conducted by service user–researchers and by clinicians, which did not enable us to test whether the information obtained from the two types of interviewer was the same. Because most service users gave positive accounts of their admission, it may be that discharge is an opportune time to engage individuals in longer-term treatment if appropriate.

For other researchers, our finding of no differences in elicited information by interviewer status indicates that studies conducted by clinicians and service user–researchers can be compared directly or analyzed together in meta-analyses.

The finding that participants were less likely to provide consent to
Table 2
Information about service users’ views of their hospital admission elicited during interviews before hospital discharge with service user–researchers or clinicians

<table>
<thead>
<tr>
<th>Variable</th>
<th>Interviewer</th>
<th>Service user–researcher (N=77)</th>
<th>Clinician (N=84)</th>
<th>Test statistic</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>N %</td>
<td>N %</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived coercion (M±SD score)a</td>
<td></td>
<td>3.0±2.0</td>
<td>2.9±2.0</td>
<td>t=0.57</td>
<td>160</td>
<td>.57</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>4.0±1.7</td>
<td>4.2±1.4</td>
<td>t=0.58</td>
<td>77</td>
<td>.56</td>
</tr>
<tr>
<td>Involuntarily admitted</td>
<td></td>
<td>2.0±1.9</td>
<td>1.8±1.7</td>
<td>t=0.43</td>
<td>82</td>
<td>.67</td>
</tr>
<tr>
<td>Perceived pressures (M±SD score)b</td>
<td></td>
<td>1.1±0.9</td>
<td>1.1±0.9</td>
<td>t=0.02</td>
<td>151</td>
<td>.98</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>1.4±0.9</td>
<td>1.3±0.8</td>
<td>t=0.37</td>
<td>72</td>
<td>.71</td>
</tr>
<tr>
<td>Involuntarily admitted</td>
<td></td>
<td>0.8±0.7</td>
<td>1.0±0.9</td>
<td>t=0.8</td>
<td>78</td>
<td>.43</td>
</tr>
<tr>
<td>Procedural justice (M±SD score)c</td>
<td></td>
<td>1.7±0.9</td>
<td>1.7±0.9</td>
<td>t=0.36</td>
<td>144</td>
<td>.72</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>2.0±0.9</td>
<td>2.3±1.0</td>
<td>t=0.15</td>
<td>70</td>
<td>.26</td>
</tr>
<tr>
<td>Involuntarily admitted</td>
<td></td>
<td>1.4±0.7</td>
<td>1.2±0.4</td>
<td>t=1.14</td>
<td>73</td>
<td>.15</td>
</tr>
<tr>
<td>Satisfaction with services (M±SD score)d</td>
<td></td>
<td>24.1±6.0</td>
<td>24.7±6.0</td>
<td>t=0.06</td>
<td>127</td>
<td>.61</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>22.0±6.0</td>
<td>22.0±7.4</td>
<td>t=0.41</td>
<td>54</td>
<td>.95</td>
</tr>
<tr>
<td>Involuntarily admitted</td>
<td></td>
<td>26.0±5.2</td>
<td>26.5±4.1</td>
<td>t=0.01</td>
<td>72</td>
<td>.69</td>
</tr>
<tr>
<td>Perceived that the admission was necessary</td>
<td></td>
<td>58 78</td>
<td>60 76</td>
<td>X²=13.13</td>
<td>1</td>
<td>.72</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>23 61</td>
<td>19 58</td>
<td>X²=0.66</td>
<td>1</td>
<td>.80</td>
</tr>
<tr>
<td>Involuntarily admitted</td>
<td></td>
<td>35 97</td>
<td>41 89</td>
<td>X²=1.95</td>
<td>1</td>
<td>.16</td>
</tr>
</tbody>
</table>

a Measured with the MacArthur Admission Experience Survey (MacArthur AES) perceived coercion scale. Possible scores range from 0 to 5, with higher scores indicating higher levels of perceived coercion.
b Measured with the MacArthur AES perceived pressures scale. Possible scores range from 0 to 4, with higher scores indicating higher levels of perceived pressures.
c Measured with the MacArthur AES procedural justice scale. Possible scores range from 1 to 4, with higher scores indicating lower levels of perceived procedural justice.
d Measured with the self-report Client Satisfaction Questionnaire (CSQ-8). Possible scores range from 8 to 32, with higher scores indicating higher levels of satisfaction.

service user–researchers has several possible explanations that would require further qualitative study. However, there are methodological and ethical difficulties involved in studying a subgroup of individuals who do not wish to participate in research. One possible explanation is that participants were reassured by their knowledge that clinicians are bound by confidentiality, even though the letter of information and consent form stated that all interviews would be confidential. In a qualitative study that examined service users’ experience of being interviewed by another service user, the interviewees reported many positive aspects of the interviews, but confidentiality and insecurity were concerns (24). A method of formalizing the confidentiality of future interviews conducted by service user–researchers could be considered.

Alternatively, potential participants may have felt more comfortable declining when consent was sought by a service user–researcher, and the 24% decline rate may be a more accurate reflection of the proportion of individuals who would prefer not to participate in research. The low decline rate of 8% when consent was sought by clinicians may have resulted from a feeling of obligation to participate. In the EUROMIA study of coercion in psychiatry in European countries, 26% of eligible individuals declined to participate; proportions ranged from 5% to 54% at the various European sites (25). Therefore, the decline rate for the service user–researchers was comparable with rates in other studies, and our finding of the 8% decline rate for clinicians may be particularly low. It has been suggested that consent sought by a clinician is associated with higher levels of perceived coercion to participate in research (26).

Strengths and limitations
One limitation of the study is that we did not include individuals with a first episode of psychosis, which may have introduced bias to the sample. Another limitation is that service users’ views of their admissions are complex, and qualitative information provided during the interview was not captured. A further limitation is that the interviews were conducted in the hospital and before discharge; research has shown that both of these interview characteristics are associated with service users’ more...
positive accounts (8). Strengths of this study include an adequately powered sample size and inclusion of both voluntarily and involuntarily admitted service users. Because the sample was drawn from consecutive admissions in three large catchment areas and at a private hospital, our results are likely to be generalizable to other mental health services.

Acknowledgments and disclosures

The project was partially funded by a grant from the Mental Health Commission in Ireland. Support was also provided by the Child and Adolescent Mental Health Service, which employed a service user-researcher part time. The authors are grateful to the clinical directors of the mental health services for facilitating this study: Siobhan Barry, M.R.C.Psych., Bernadette Mangan, M.R.C.Psych., Anthony McCarthy, M.R.C.Psych., Freda O'Connell, M.R.C.Psych., and Justin Brophy, M.R.C.Psych. They also thank Darina Brennan, M.L.I.S., Ph.D., for managing the randomization and Darach Murphy for conducting interviews on behalf of SOURCE. They are grateful to the late Eadhaild O'Callaghan, D.Sc., F.R.C.Psych., for facilitating this study. The project would not have been possible without the administrative skills of Karen Colbe of SOURCE.

Mr. Shannon's work toward a doctorate in the area of seclusion is funded by the Mental Health Commission. The other authors report no competing interests.

References


18. Andreasen NC: The Scale for the Assessment of Positive Symptoms (SAPS). Iowa City, University of Iowa, 1984

19. Andreasen NC: The Scale for the Assessment of Negative Symptoms (SANS). Iowa City, University of Iowa, 1985


Part VI: CAREGIVER PARTICIPATION - QUANTITATIVE

Appendix XVIII: Caregiver information sheet
Appendix XIX: Caregiver letter of consent
Appendix XX: Adapted MacArthur Admission Experience Survey
Appendix XXI: Involvement Evaluation Questionnaire
Appendix XXII: General Health Questionnaire
Appendix XXIII: Brief COPE
Appendix XXIV: Level of Expressed Emotion Scale – Relative version
Appendix XXV: Social Problem-Solving Inventory
Dear ____________,

We are undertaking a project examining the views and experiences of family members or partners with regard to their relatives/partners admission to hospital. This project will allow family members/partners an opportunity to discuss what supports they would find most helpful.

This project is being undertaken by Ms. Veronica Ranieri, Mr. Kevin Madigan, Dr. Brian O’Donoghue, and Dr. Kevin Tierney.

Participation in this study is completely voluntary and so you are not obliged to participate and your decision will not affect your relative/partner’s care. The data from the completed questionnaires will be stored in accordance with the Data Protection Act Best Practices in Scientific Research.

We would hope that after meeting with you, we will have a number of suggestions to help improve the mental health services. Therefore, the findings from the project may published or presented at a conference, however, you or your relative/partner’s will not be identifiable or recognizable from this. The data collected will form a PhD thesis for Veronica Ranieri, PhD candidate at Trinity College Dublin and member of SOURCE.

If you would like to participate, we would be grateful if you could please sign the attached consent form. If you have any questions regarding the study, please do not hesitate to contact me on 086 1906979 or at ranieriv@tcd.ie. If, at any time, you feel distressed, please contact a member of the Cluain Mhuire family Centre on 01-2172100.

Yours Sincerely,

Veronica Ranieri
School of Psychology
Áras an Phíarsaigh,
Trinity College Dublin
Dublin 2
T: 086 1906979 / E: ranieriv@tcd.ie

Dr. Kevin Tierney
School of Psychology
Áras an Phíarsaigh
Trinity College Dublin
Dublin 2
T: 01 896 2609 / E: tiernen@tcd.ie
Title: Caregivers’ Perspectives of their Admission

I have met with the researchers and I have been provided with the information sheet on the project which involves an interview about my relatives/partners admission to hospital.

I understand the nature and purpose of this study and I have had the opportunity to ask questions.

I am willing to participate in this project.

Name (PRINT): ___________________________  Date: ____________

Signature: _______________________________  Date: ____________

Witness: ________________________________  Date: ____________

Thank you for taking part in this project.
## MacArthur Admission Interview – Adapted for Caregivers

### Perceived Coercion

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did anyone else have more influence than your relative on whether he/she came into hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Did your relative have a lot of control over whether he/she went into the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Did your relative choose to come into the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Did your relative feel free to do what he/she wanted about coming into the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Was it your relative’s idea to come into the hospital?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Perceived Pressures

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did anyone try to talk him or her into going to hospital or being admitted?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Did anyone offer or promise him or her anything?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Did anyone threaten him or her?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Did anyone force him or her?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Procedural Justice
(these four questions are to be asked regarding each person involved with the decision)

1. To what extent did those involved in the admission act out of concern? (very much, mostly, a little, not at all)

2. With how much respect did those involved in the admission treat your relative with? (very, some, a little, none)

3. How seriously did those involved consider what your relative had to say (very, some, a little, none)?

4. How fairly was your relative treated? (very fair, mostly fair, mostly unfair, very unfair)
IEQ-EU

Involvement Evaluation Questionnaire

European Version

©2001 AH Schene, B van Wijngaarden & MWJ Koeter
Department of Psychiatry
Academic Medical Center
Amsterdam, The Netherlands
INVolvEMENT EVALUATION
QUESTIONNAIRE

Introduction

In the field of psychiatric care, attention has been concentrated almost exclusively on the patients themselves. In recent years, however, more concern has been shown towards the families, friends and others involved.

You too are involved in the care of someone with mental health problems and this questionnaire has been designed to assess the personal consequences of such a situation for carers like yourself.

Completing the questionnaire

The questionnaire is divided into 8 sections, each representing a different aspect of caring. Each part is headed by a brief explanatory paragraph to lead you into the theme of the section.

Only one answer is possible for each question, unless otherwise indicated - please tick accordingly. In some cases, we will ask you to fill in a few personal details, such as your age.

It is quite possible that in some cases, a question will not be relevant to your particular circumstances. The questionnaire will clearly indicate, therefore, which questions you can ignore and at which point you should start again.

The consequences of your caring for someone who has mental health problems might have existed for several years already, but it is important to bear in mind that this questionnaire is mostly concerned with an analysis of the current situation. Most of the questions, therefore, cover your experiences during the past four weeks, whilst a few questions are about your more long-term experience. The questions themselves will make this clear.

All information will be treated confidentially, and you do not have to give your name if you do not wish to. If there are questions which you would prefer not to answer, we will, of course, respect your wishes - in this case, however, please write 'no answer' next to the question.

Take your time to answer each question in turn and remember that what matters most of all is that your answers truly reflect your own personal experience.
Before we turn to the matter of your own experiences, we would first like to have some general information about you personally and about the relative/friend you are caring for.

1. What is your age?
   I am .... years of age.

2. Sex?
   [ ] female
   [ ] male

3. Your education/training?

4. What is your civil status?
   I am:
   [ ] single
   [ ] married/in a long-term partnership
   [ ] divorced
   [ ] widowed

5. Do you live alone or with others?
   [ ] I live alone (PROCEED TO QUESTION 7)
   [ ] I live with my spouse/partner and/or children
   [ ] I live with my parents and/or sisters/brothers
   [ ] I live with other relatives
   [ ] I live with friends
   [ ] other (please indicate) ...........................................

6. How many people, including yourself, are there in your household?
   My household consists of .... (no.) people

7. What is your relative/friend's age?
My relative/friend is ___ years of age.

8. My relative/friend's sex is:
   [ ] female
   [ ] male

9. When did your relative/friend's mental health problems start?
   That was in ___ (year)

10. Is your relative/friend currently receiving help for his/her mental health problems?
    Please note that more than one answer is possible.
    [ ] I do not know
    [ ] no professional help
    [ ] yes, from G.P./family doctor
    [ ] yes, from a social worker
    [ ] yes, from an occupational therapist
    [ ] yes, at the community mental health centre/from the community mental health team
    [ ] yes, from a psychologist or cognitive/behavioural therapist
    [ ] yes, as an outpatient at a psychiatric hospital or the psychiatric department of a general hospital
    [ ] yes, in a psychiatric day hospital
    [ ] yes, as an inpatient in a psychiatric hospital or the psychiatric department of a general hospital
    [ ] yes, living in supported housing
    [ ] yes, other (please specify ................................)

11. What is your precise relationship with your relative/friend?
    I am her/his:
    [ ] mother/father (step, foster and adoptive parents included)
    [ ] daughter/son
    [ ] sister/brother
    [ ] other relative
    [ ] wife/husband, partner or girl/boy friend
    [ ] friend
    [ ] neighbour
    [ ] colleague/fellow student
    [ ] other (please indicate) ...........................................

12. Is your relative/friend part of your household?
13. How many days have you and your relative/friend lived together at the same address during the past four weeks?

[ ] no
[ ] yes

[ ] none
[ ] some, namely ...................(no.) days
[ ] the full four weeks

14. What is your family's approximate net income (wage/salary, welfare benefits, pension etc.) after deductions for tax, national insurance etc.?

[ ] less than £300 per month (EUR 500 per month)
[ ] £300 - £500 per month (EUR 500 - EUR 800 per month)
[ ] £500 - £900 per month (EUR 800 - EUR 1400 per month)
[ ] £900 - £1500 per month (EUR 1400 - EUR 2400 per month)
[ ] £1500 - £2250 per month (EUR 2400 - EUR 3500 per month)
[ ] more than £2250 per month (more than EUR 3500 per month)

15. What has been your average weekly telephone or personal contact with your relative/friend, over the past four weeks?

[ ] less than 1 hour a week (PROCEED TO QUESTION 37)
[ ] 1-4 hours a week
[ ] 5-8 hours a week
[ ] 9-16 hours a week
[ ] 17-32 hours a week
[ ] more than 32 hours a week
The following questions are about the encouragement and care you have given to your relative/friend during the past four weeks.

16. How often during the past four weeks have you **encouraged** your relative/friend to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?

- [ ] never
- [X] sometimes
- [ ] regularly
- [X] often
- [ ] (almost) always

17. How often during the past four weeks have you **helped** your relative/friend take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?

- [ ] never
- [ ] sometimes
- [ ] regularly
- [X] often
- [ ] (almost) always

18. How often during the past four weeks have you **encouraged** your relative/friend to eat enough?

- [ ] never
- [ ] sometimes
- [ ] regularly
- [ ] often
- [ ] (almost) always

19. How often during the past four weeks have you **encouraged** your relative/friend to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, household chores)?

- [ ] never
- [ ] sometimes
- [ ] regularly
- [ ] often
- [ ] (almost) always
20. How often during the past four weeks have you **accompanied** your relative/friend on some kind of outside activity, because he/she did not dare to go alone?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

21. How often during the past four weeks have you **ensured** that your relative/friend has taken the required medicine?

[ ] not relevant: relative/friend has no medicines
[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

22. How often during the past four weeks have you **guarded** your relative/friend from committing dangerous acts (i.e. setting something alight, leaving the gas on, forgetting to stub cigarettes out etc.)?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

23. How often during the past four weeks have you **guarded** your relative/friend from self-inflicted harm (i.e. cutting her/himself, excessive medicine intake, burning, suicide attempt etc.)?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

24. How often during the past four weeks have you **ensured** that your relative/friend received sufficient sleep?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always
25. How often during the past four weeks have you guarded your relative/friend from drinking too much alcohol?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

26. How often during the past four weeks have you guarded your relative/friend from taking illegal drugs?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

27. How often during the past four weeks have you carried out tasks normally done by your relative/friend (household chores, financial matters, shopping, cooking etc.)?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

28. How often during the past four weeks have you encouraged your relative/friend to get up in the morning?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

29. How often during the past four weeks has your relative/friend disturbed your sleep?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always
The following questions are about how you have got on with your relative/friend in the past four weeks.

30. **How often during the past four weeks has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?**

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] (almost) always

31. **How often during the past four weeks has your relative/friend caused a quarrel?**

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] (almost) always

32. **How often during the past four weeks have you been annoyed by your relative/friend's behaviour?**

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] (almost) always

33. **How often during the past four weeks have you heard from others that they have been annoyed by your relative/friend's behaviour?**

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] (almost) always
34. How often during the past four weeks have you felt threatened by your relative/friend?

- never
- sometimes
- regularly
- often
- (almost) always

35. How often during the past four weeks have you thought of moving out, as a result of your relative/friend's behaviour?

- never
- sometimes
- regularly
- often
- (almost) always

36. How often during the past four weeks have you been able to pursue your own activities and interests (e.g. work, school, hobbies, sports, visits to family and friends)?

- never
- sometimes
- regularly
- often
- (almost) always

The following questions are about the worries which may arise from your involvement with a relative/friend who has mental health problems.

37. How often during the past four weeks have you worried about your relative/friend's safety?

- never
- sometimes
- regularly
- often
- (almost) always
38. How often during the past four weeks have you worried about the kind of help/treatment your relative/friend is receiving?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

39. How often during the past four weeks have you worried about your relative/friend's general health?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

40. How often during the past four weeks have you worried about how your relative/friend would manage financially if you were no longer able to help?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

41. How often during the past four weeks have you worried about your relative/friend's future?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

42. How often during the past four weeks have you worried about your own future?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always
43. To what extent have your relative/friend's mental health problems been a burden to you during the past four weeks?

[ ] no burden at all
[ ] a slight burden
[ ] a fairly heavy burden
[ ] a heavy burden
[ ] a very heavy burden

44. Have you got used to your relative/friend having mental health problems?

[ ] no
[ ] a little
[ ] fairly well
[ ] very well
[ ] completely

45. How often have you felt able to cope with your relative/friend's mental health problems?

[ ] never
[ ] sometimes
[ ] regularly
[ ] often
[ ] (almost) always

46. Has your relationship with your relative/friend changed since the onset of the mental health problems?

[ ] no
[ ] a little
[ ] rather a lot
[ ] a lot
[ ] a great deal
Please read the questions below and each of the four possible answers. We want to know how your health has been in general over the last four weeks. Please answer all the questions by circling the response that best applies to you.

Have you recently:

55. been able to concentrate on what you're doing? better than usual  same as usual  less than usual  much less than usual

56. lost much sleep over worry? not at all  no more than usual  rather more than usual  much more than usual

57. felt that you are playing a useful part in things? more so than usual  same as usual  less so than usual  much less than usual

58. felt capable of making decisions about things? more so than usual  same as usual  less so than usual  much less capable

59. felt constantly under strain? not at all  no more than usual  rather more than usual  much more than usual

60. felt you couldn't overcome your difficulties? not at all  no more than usual  rather more than usual  much more than usual

61. been able to enjoy your normal day-to-day activities? more so than usual  same as usual  less so than usual  much less than usual

62. been able to face up to your problems? more so than usual  same as usual  less able than usual  much less able

63. been feeling unhappy or depressed? not at all  no more than usual  rather more than usual  much more than usual

64. been losing confidence in yourself? not at all  no more than usual  rather more than usual  much more than usual

65. been thinking of yourself as a worthless person? not at all  no more than usual  rather more than usual  much more than usual

66. been feeling reasonably happy, all things considered? more so than usual  same as usual  less so than usual  much less than usual
67. Are you receiving help from your G.P./family doctor for any of these complaints?
   [ ] yes
   [ ] no

68. Are you receiving help from a social worker, a psychologist, a psychiatrist or an outpatient department for any of these complaints?
   [ ] yes
   [ ] no

69. Are you taking any kind of medicine for these complaints?
   [ ] yes
   [ ] no
The items listed in this questionnaire cannot, of course, cover all your experiences. If you would like to make any further comments, therefore, please feel free to write them in the space below.

Comments:

It is important for the purposes of this study that all the questions that apply to you personally, are answered.

We would appreciate it, therefore, if you would carefully check that no questions have been overlooked.

Please accept our sincere thanks for your help and co-operation.
# BRIEF COPE

**INSTRUCTIONS:** We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what **you** generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you **usually** do when you are under a lot of stress.

Then respond to each of the following items by blackening one number on your answer sheet for each, using the response choices listed just below. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU— not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I usually <strong>don't</strong> do this at all</td>
<td>I usually do this a little bit</td>
<td>I usually do this a medium amount</td>
<td>I usually do this a lot</td>
</tr>
<tr>
<td>1.</td>
<td>I've been concentrating my efforts on doing something about the situation I'm in.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2.</td>
<td>I've been trying to come up with a strategy about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3.</td>
<td>I've been trying to see it in a different light, to make it seem more positive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4.</td>
<td>I've been accepting the reality of the fact that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5.</td>
<td>I've been making jokes about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6.</td>
<td>I've been trying to find comfort in my religion or spiritual beliefs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7.</td>
<td>I've been getting emotional support from others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8.</td>
<td>I've been trying to get advice or help from other people about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9.</td>
<td>I've been turning to work or other activities to take my mind off things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10.</td>
<td>I've been saying to myself &quot;this isn't real.&quot;</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11.</td>
<td>I've been saying things to let my unpleasant feelings escape.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12.</td>
<td>I've been using alcohol or other drugs to make myself feel better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13.</td>
<td>I've been giving up trying to deal with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>14. I've been criticizing myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I've been learning to live with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I've been taking action to try to make the situation better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I've been thinking hard about what steps to take.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I've been looking for something good in what is happening.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I've been making fun of the situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I've been praying or meditating.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I've been getting comfort and understanding from someone.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. I've been getting help and advice from other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. I've been refusing to believe that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. I've been expressing my negative feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. I've been using alcohol or other drugs to help me get through it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. I've been giving up the attempt to cope.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. I've been blaming myself for things that happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
LEVEL OF EXPRESSED EMOTION SCALE

Relative Version

John D. Cole, Ph.D.
Shahe S. Kazarian, Ph.D.

Instructions:

The following are a number of statements that describe the way in which you may act towards someone. Please read each statement and indicate whether you have been acting in these ways towards your relative (son, daughter, spouse, etc.) over the past three months.

Mark your answers on the separate Answer Sheet provided. Simply circle the (T) box if you feel that the item is TRUE. Circle the (F) box if you feel the item is FALSE. It is important to make sure that the statement number agrees with the number of your response on the Answer Sheet.
1. I say I understand if sometimes he/she doesn't want to talk.
2. I calm him/her down when he/she is upset.
3. I say he/she lacks self-control.
4. I am tolerant with him/her even when he/she doesn't meet my expectations.
5. I don't butt into his/her conversations.
6. I don't make him/her nervous.
7. I say he/she just wants attention when he/she says he/she is not well.
8. I make him/her feel guilty for not meeting my expectations.
9. I am not overprotective with him/her.
10. I lose control of my temper.
11. I am sympathetic towards him/her when he/she is not feeling well.
12. I can see his/her point of view.
13. I am always interfering.
14. I don't panic when things start going wrong.
15. I encourage him/her to seek outside help when he/she is not feeling well.
16. I don't feel that he/she is causing me a lot of trouble.
17. I don't insist on doing things with him/her.
18. I can't think straight when things go wrong.
19. I don't help him/her when he/she is upset or feeling unwell.
20. I put him/her down if he/she doesn't live up to my expectations.
21. I don't insist on being with him/her all the time.
22. I blame him/her for things not going well.
23. I make him/her feel valuable as a person.
24. I can't stand it when he/she is upset.
25. I leave him/her feeling overwhelmed.
26. I don't know how to handle his/her feelings when he/she is not feeling well.
27. I say he/she causes his/her troubles to occur in order to get back at me.
28. I understand his/her limitations.
29. I often check up on him/her to see what he/she is doing.
30. I am able to be in control in stressful situations.
31. I try to make him/her feel better when he/she is upset or ill.
32. I am realistic about what he/she can and cannot do.
33. I am always nosing into his/her business.
34. I hear him/her out.
35. I say it is not OK to seek professional help.
36. I get angry with him/her when things don't go right.
37. I always have to know everything about him/her.
38. I make him/her feel relaxed when I am around.
39. I accuse him/her of exaggerating when he/she says he/she is unwell.
40. I will take it easy with him/her, even if things aren't going right.
41. I insist on knowing where he/she is going.
42. I get angry with him/her for no reason.
43. When he/she is upset, I am a considerate person.
44. I support him/her when he/she needs it.
45. I butt into his/her private matters.
46. I can cope well with stress.
47. I am willing to gain more information to understand his/her condition, when he/she is not feeling well.
48. I am understanding if he/she makes a mistake.
49. I don't pry into his/her life.
50. I am patient with him/her when he/she is not well.
51. I don't blame him/her when he/she is feeling unwell.
52. I expect too much from him/her.
53. I don't ask a lot of personal questions.
54. I make matters worse when things aren't going well.
55. I often accuse him/her of making things up when he/she is not feeling well.
56. I "fly off the handle" when he/she doesn't do something well.
57. I get upset when he/she doesn't check in with me.
58. I get irritated when things don't go right.
59. I try to reassure him/her when he/she is not feeling well.
60. I expect the same level of effort from him/her, even if he/she doesn't feel well.
THE LEE SCALE (Relative Version): ANSWER SHEET

YOUR NAME: ___________________ AGE: ____ SEX: (circle one) Male Female DATE: __________

MARITAL STATUS: (circle one)
Single Married/Common-Law Separated Divorced Widowed

Indicate your relationship to your relative:
(circle one)
Mother Father Brother Sister Spouse Friend Other (Please Specify) ______________________

Has your relative been living with you during the past three months?
(circle one) Yes No

How many waking hours on a typical weekday have you been spending with your relative
during the past three months? ___ hours per week day

How many waking hours on a typical weekend have you been spending with your relative
during the past three months? ___ hours per weekend

Instructions for each item:
Circle the "T" box if you feel the item is TRUE
Circle the "F" box if you feel the item is FALSE

<table>
<thead>
<tr>
<th>1</th>
<th>T</th>
<th>F</th>
<th>16</th>
<th>T</th>
<th>F</th>
<th>31</th>
<th>T</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>T</td>
<td>F</td>
<td>17</td>
<td>T</td>
<td>F</td>
<td>32</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>T</td>
<td>F</td>
<td>18</td>
<td>T</td>
<td>F</td>
<td>33</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>4</td>
<td>T</td>
<td>F</td>
<td>19</td>
<td>T</td>
<td>F</td>
<td>34</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>5</td>
<td>T</td>
<td>F</td>
<td>20</td>
<td>T</td>
<td>F</td>
<td>35</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>6</td>
<td>T</td>
<td>F</td>
<td>21</td>
<td>T</td>
<td>F</td>
<td>36</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>7</td>
<td>T</td>
<td>F</td>
<td>22</td>
<td>T</td>
<td>F</td>
<td>37</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>8</td>
<td>T</td>
<td>F</td>
<td>23</td>
<td>T</td>
<td>F</td>
<td>38</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>9</td>
<td>T</td>
<td>F</td>
<td>24</td>
<td>T</td>
<td>F</td>
<td>39</td>
<td>T</td>
<td>F</td>
</tr>
<tr>
<td>10</td>
<td>T</td>
<td>F</td>
<td>25</td>
<td>T</td>
<td>F</td>
<td>40</td>
<td>T</td>
<td>F</td>
</tr>
</tbody>
</table>

Copyright © 1993 John D. Cole, Ph.D. & Shahe S. Kazarian, Ph.D.
Page 4
**Instructions:** Below are some ways that you might think, feel, and act when faced with problems in everyday living. We are not talking about the ordinary hassles and pressures that you handle successfully every day. In this questionnaire, a problem is something important in your life that bothers you a lot, but you don’t immediately know how to make it better or stop it from bothering you so much. The problem could be something about yourself (such as your thoughts, feelings, behavior, health, or appearance), your relationships with other people (such as your family, friends, teachers, or boss), or your environment and the things you own (such as your house, car, property, or money). Please read each statement carefully and choose one of the numbers below that best shows how much the statement is true of you. See yourself as you usually think, feel, and act when you are faced with important problems in your life these days. Circle the number that is the most true of you. Do not erase if you want to change an answer, instead put an “X” through the answer you wish to change. Try to answer all of the questions.

<table>
<thead>
<tr>
<th></th>
<th>Not at All True of Me</th>
<th>Slightly True of Me</th>
<th>Moderately True of Me</th>
<th>Very True of Me</th>
<th>Extremely True of Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. I feel threatened and afraid when I have an important problem to solve.
2. When making decisions, I do not evaluate all my options carefully enough.
3. I feel nervous and unsure of myself when I have an important decision to make.
4. When my first efforts to solve a problem fail, I know if I persist and do not give up too easily, I will be able to eventually find a good solution.
5. When I have a problem, I try to see it as a challenge, or opportunity to benefit in some positive way from having the problem.
6. I wait to see if a problem will resolve itself first, before trying to solve it myself.
7. When my first efforts to solve a problem fail, I get very frustrated.
8. When I am faced with a difficult problem, I doubt that I will be able to solve it on my own no matter how hard I try.
9. Whenever I have a problem, I believe that it can be solved.
10. I go out of my way to avoid having to deal with problems in my life.
11. Difficult problems make me very upset.
12. When I have a decision to make, I try to predict the positive and negative consequences of each option.
13. When problems occur in my life, I like to deal with them as soon as possible.
14. When I am trying to solve a problem, I go with the first good idea that comes to mind.
15. When I am faced with a difficult problem, I believe that I will be able to solve it on my own if I try hard enough.
16. When I have a problem to solve, one of the first things I do is get as many facts about the problem as possible.
17. When a problem occurs in my life, I put off trying to solve it for as long as possible.
18. I spend more time avoiding my problems than solving them.
19. Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.
20. When I have a decision to make, I do not take the time to consider the pros and cons of each option.
21. After carrying out a solution to a problem, I try to evaluate as carefully as possible how much the situation has changed for the better.
22. I put off solving problems until it is too late to do anything about them.
23. When I am trying to solve a problem, I think of as many options as possible until I cannot come up with any more ideas.
24. When making decisions, I go with my "gut feeling" without thinking too much about the consequences of each option.
25. I am too impulsive when it comes to making decisions.
Part VII:

CAREGIVER PARTICIPATION - QUALITATIVE

Appendix XXVI: Caregiver information sheet
Appendix XXVII: Caregiver letter of consent
Appendix XXVIII: Interview Schedule
Appendix XXIX: Debriefing sheet
Appendix XXX: Connecticut’s Civil Commitment Law
Dear Participant,

We are undertaking a project examining the views and experiences of family members regarding their relative’s admission to hospital. This project will allow you an opportunity to discuss your experiences in your own words.

This project is being undertaken by Ms. Veronica Ranieri, Professor Larry Davidson (Yale University), and Dr. Kevin Tierney.

Participation in this study is completely voluntary. You are not obliged to participate and your decision will not affect your relative’s care. The interviews will be audio-recorded and the recordings will be stored anonymously and in accordance with the Data Protection Act Best Practices in Scientific Research.

We hope that after meeting with you, we will have a number of suggestions to help improve the mental health services. Therefore, the findings from the project may be published or presented at a conference, however, you or your relative will not be identifiable or recognizable from this. The data collected will form a PhD thesis for Veronica Ranieri, PhD candidate at Trinity College Dublin.

If you would like to participate, we would be grateful if you could please sign the attached consent form. If you have any questions regarding the study, please do not hesitate to contact me on 087 9408943 or at ranieriv@tcd.ie. If, at any time, you feel distressed, please contact a member of Shine at 01 8601620 or on 1890621631.

Yours Sincerely,

Veronica Ranieri  
School of Psychology  
Áras an Phiarsaigh,  
Trinity College Dublin  
Dublin 2  
T: 087 9408943 / E: ranieriv@tcd.ie

Dr. Kevin Tierney  
School of Psychology  
Áras an Phiarsaigh  
Trinity College Dublin  
Dublin 2  
T: 01 896 2609 / E: tiernen@tcd.ie
Title: Caregivers' Perspectives of their Admission

I have met with the researchers and I have been provided with the information sheet on the project which involves an interview about my relative’s admission to hospital.

I understand the nature and purpose of this study and I have had the opportunity to ask questions.

I am willing to participate in this project.

Name (PRINT): ___________________________ Date: ___________

Signature: ___________________________ Date: ___________

Witness: ___________________________ Date: ___________

Thank you for taking part in this project.
Interview Schedule

1. Please tell me about how [relative]'s admission happened.

2. Did you experience any difficulty in getting medical help for him/her? If so, in what aspect(s)?

3. Do you feel that [relative] had control over whether he/she was admitted? In what way?

4. Was it his/her idea to come into hospital?

5. How do you feel your relative was treated during the admission? (respect, fairness, concern, listened to)

6. Do you feel your relative was (1) forced into hospital? (2) Or threatened?

7. Upon reflection, do you feel there was a positive aspect to the admission? If so, what was it?

8. Is there any aspect of the admission that you are not happy with? If so, what aspect(s)?

9. We are just coming to the end of the interview. Is there anything which you feel you would like to say that we have not spoken about?
Dear Participant,

Thank you for taking part in our study. Your views will help inform us of family members’ experiences of their relative’s admission to a mental health unit.

This project is being undertaken by Ms. Veronica Ranieri, Dr. Kevin Tierney & Prof. Larry Davidson (Yale University).

The interview was audio-recorded and the recordings will be stored anonymously and in accordance with the Data Protection Act Best Practices in Scientific Research.

If, at any time, you feel distressed, please contact a member of Shine at 01 8601620 or on 1890621631.

If you have any questions regarding the study, please do not hesitate to contact me on 087 9408943 or at ranieriv@tcd.ie.

Yours Sincerely,

Veronica Ranieri
School of Psychology
Áras an Phiaraisigh, Trinity College Dublin
Dublin 2
T: 087 9408943
E: ranieriv@tcd.ie

Dr. Kevin Tierney
School of Psychology
Áras an Phiaraisigh, Trinity College Dublin
Dublin 2
T: 01 896 2609
E: tiernen@tcd.ie
Connecticut’s Involuntary Civil Commitment Law

For an individual to enter hospital involuntarily with a psychiatric illness in the state of Connecticut, he or she must be deemed either (1) an imminent danger to self or others or (2) gravely disabled and negligent of self-care. This may also include individuals who are unable to consent to treatment due to mental illness. An individual can be involuntarily admitted in one of two ways; by court mandate or by emergency certification.

A court-ordered commitment occurs in three steps (CGS § 17a-497; CGS § 17a-498):

1) An application for involuntary commitment is firstly filed with the probate court by any member of the public who has observed the individual in question.

2) The probate court appoints two doctors, one of which must be a psychiatrist, to examine the individual within 10 days and determine whether he or she is suffering from a psychiatric disorder that requires civil commitment. Upon this examination, both physicians must complete a form (Department of Mental Health and Addiction Service form) and return it to the court. On this form, the doctors must state the alleged mental illness, the necessity and availability of treatment, whether the illness causes impairment to the individual’s functioning and whether it interferes with the individual’s ability to consent to treatment. A warrant may be issued by the court if the individual refuses to be medically examined.

3) Finally, a court hearing must take place within 10 working days of the application. The purpose of the hearing is to examine the evidence presented by the court-appointed physicians and the individual’s legal representative and, based on this evidence, either mandate involuntary commitment or release the individual. Advanced notice of the court hearing must be given to the individual and the individual’s family or friends (caregivers). He or she must attend the court hearing, however, has the right to private or court-appointed counsel, cross-examine witnesses and access all hospital records prior to the hearing. Furthermore, the individual is permitted to enter hospital voluntarily prior to a court ruling.

The individual, his or her counsel or the probate judge may request three judges to reside over the hearing. In this case, two of three judges must be in favour of involuntary hospitalisation
for it to occur. Alternatively, the hearing may take place in the hospital in which the person has been admitted if at least one of the court-appointed physicians deems that travel to a court would impinge on the individual’s health or could be dangerous to the individual or others. The period of involuntary commitment may last for the length of the illness, until hospital discharge or revocation of an involuntary legal status (Orlando, 2013).

According to Connecticut’s civil commitment law, an individual may be civilly committed to a general hospital by emergency commitment if in need of immediate treatment. This may be done in three ways (CGS § 17a-502; CGS § 17a-503):

(a) Similarly to the court-ordered civil commitment procedure outlined above, an application for emergency confinement may be made by any member of the public. This must be made in good faith and with the belief that the individual has a psychiatric disability which necessitates immediate treatment to prevent further endangering him or herself or any other member of the public.

(b) A police officer may also bring a person to hospital for an emergency examination if he or she believes that it is necessary.

(c) A certificate for an emergency examination and plausible confinement may be issued by a health professional (physician, licensed psychologist, advanced practice registered nurse or certain licensed clinical social workers) with specialized training in psychiatric evaluations.

Upon receipt of an application for emergency commitment, a warrant may be issued to the police who will take the individual into custody and bring him or her to a general hospital. On arrival to the hospital, the individual must be examined within 24 hours (or 48 hours if detained under a physician’s certificate). The individual must be released within 72 hours unless involuntarily committed by court order or under a physician’s emergency certificate. A physician may detain an individual for 15 days without a court order following examination if he or she believes that the individual meets the criteria for emergency commitment. The certificate must include the examination date, the results of the examination, the physician’s opinion regarding treatment and the necessity for immediate commitment. This period may be extended by a further 15 days if an application for civil commitment is made before the end of the physician’s certificate timeline.
Upon emergency confinement, the individual must be informed that he or she has three rights: the right to counsel (court-appointed if required), the right to seek advice from counsel, and the right to request a probable cause hearing. If requested, the probable cause hearing must take place within 72 hours of the request in writing and must precede the commitment hearing. Again, the individual may be present and has the right to an attorney to represent them and cross-examine witnesses. Similarly to a commitment hearing, a probable cause hearing must determine whether the individual requires continued involuntary hospitalisation for the treatment of a mental disorder whilst taking account of the person’s condition at the time of the admission and possible side effects if on medication. If the court determines that the individual does not fit the criteria for further involuntary detention, the individual must be immediately discharged by the hospital director. The individual may, however, choose to enter hospital voluntarily at any point prior to the judgement from the court hearing. An application for involuntary hospitalisation may be filed in the event that the individual refuses to adhere to a treatment regime and is deemed dangerous (to oneself or others). If the individual demands to be discharged in this circumstance, he or she may be detained under an emergency certificate until a probable cause hearing. It is the hospital’s responsibility to inform patients annually of their right to a court hearing.

Two constitutional clauses appear in Connecticut’s commitment law as a means of protection to those who have had an application for involuntary detention made against them: the writ of habeas corpus and penalties for wrongfully causing commitment. In other words, service users have a right to appeal the probate court’s decision regarding commitment to the Superior Court (CGS § 17a-524; CGS § 17a-525). Furthermore, anyone who falsifies information leading to a commitment or wilfully and maliciously causes, aids or attempts to induce an unjustified civil commitment may receive a maximum sentence of five years of imprisonment and a $1,000 fine (CGS § 17a-504).

**Conservatorship**

Following civil commitment, caregivers may apply for a conservatorship of person and/or estate should the service user be unable to administer these due to an incapacitating illness. In order to do so, caregivers (petitioners) must apply to the probate court who will then arrange
for a hearing to occur within 7 days of filing such application. The service user will be appointed an attorney should he or she be unable to financially avail of such. The court will then notify the service user (respondent), the service user’s next of kin and attorney within a minimum of five days prior to the hearing. At the court hearing, the following three topics will be discussed: the service user’s medical or psychiatric condition, the service user’s ability to oversee his or her personal and financial affairs and the extent to which the service user is able to do so without the need for a conservator. It is the petitioner’s responsibility to arrange at least one medical consultation within 45 days of the hearing. The court may, however, request a secondary consultation with a court-appointed physician, psychiatrist or psychologist, which the service user is entitled to refuse. During the hearing, the probate judge must regard the service user’s general level of capability and ability to express his or her preferences for personal or financial care, review his or her past preferences for care and daily life as outlined by both the service user and family as well as cultural background. Furthermore, the judge’s decision must determine whether to maintain continuity of care and/or environment, previously established personal or financial care plans as well as consider the availability of support services for the service user.

In the event that the probate court identifies, by means of considerable evidence, that the respondent is unable to maintain his or her personal and/or financial affairs alone and that the least inhibitive and intrusive method of helping the individual is by conservatorship, the probate court judge will appoint a conservator of person and/or of the estate. A conservator is, therefore, an individual who has been entrusted by the probate court to oversee the respondent’s affairs after he or she has been deemed incapable of doing so by the probate court. The conservator is tasked with the general care of the individual and his or her personal effects. The power of the conservator extends to providing consent for the respondent’s medical treatment and relocating the respondent’s residence to Connecticut (where applicable and approved by the probate court). The conservator must, however, promote the service user to achieve independence and self-reliance. He or she must also establish and voice the service user’s viewpoint and reach decisions that are compatible with both the service user’s and healthcare representative’s viewpoints.

A conservatorship may be temporary, involuntary or voluntary. A temporary conservatorship may be appointment without a hearing in the event of an emergency which is certified by a physician’s report (Form PC-302). This emergency appointment may only occur when a delay
may lead to serious and irreversible damage to the service user’s mental or physical health or financial and legal affairs. Following this appointment, the probate court must convene a court hearing within three days and notify the service user of such within two days. The purpose of the hearing is to confirm, modify or revoke the conservatorship as outlined above while balancing the service user’s need for care and right to independence. A temporary conservatorship lapses after 30 days. It may, nevertheless, remain in effect, if an application for a permanent involuntary conservatorship (Form PC-300) has been filed, for a further 30 days or until a court hearing for such conservatorship has taken place. Alternatively, a service user may request a voluntary conservatorship of person and/or the estate (Form PC-301). This conservatorship is also conditional to the approval of both the probate court and the individual to whom it is potentially entrusted.

The conserved person has the right to petition the probate court for a release from conservatorship invariably. Additionally, conservators must submit a report detailing their progress and endeavours in promoting the conserved person’s independence as well as information pertaining to their health yearly. Similarly to an application for civil commitment, Connecticut’s mental health law offers some protection to service users for whom a conservatorship is being requested. Any individual who fraudulently or maliciously induces a conservatorship by wrongfully applying or falsely testifying is subject to criminal prosecution.

Wardship

In Ireland, the equivalent of a conservatorship is referred to as a Ward Of Court (WOC). A wardship is granted only in the event that the proposed ward is unable to care for his or her personal, financial or legal needs due to severe illness. This process is initiated by a petitioner (usually a family member) who files a petition to the Wards of Court office. This petition must be accompanied by medical affidavits of two medical physicians testifying that the individual requires the protection of the court. Following receipt of the petition, an inquiry order is launched by the high court. This inquiry consists of an examination by the President’s medical officer that confirms or opposes the need for wardship. If the officer supports the petition for wardship, notice of wardship is rendered personally onto the individual. The individual has a right to object to the proposed wardship in writing to the registrar of the Ward of Courts. All evidence for and against the wardship is acquired for a high court hearing. Should the court
find grounds for wardship, a declaration order will be released placing the individual into protection. A committee will be assigned to care for the ward’s personal, financial and legal needs and a case officer will oversee the everyday running of the committee. A ward can request to be discharged from the protection of the court. This must requested in writing and must be accompanied by medical evidence showing that the ward is mentally able to care for his or her own personal, legal and financial needs. However, if the service user entrusted a relative with his or her care at a time when he or she was sound of mind, his or her care is awarded according to an enduring Power Of Attorney (POA) contract.