# Family members' experiences of schizophrenic disorders and violence

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#### **OVERVIEW**

This thesis is presented in three parts. Part One comprises a review of the literature considering the targets of violence from individuals with mental health problems. The review demonstrated that family members are often victims of violence from their mentally ill relatives. Explanations for this increased risk and the consequences of this violence were explored. Part Two is an empirical paper which investigated family members' experiences of schizophrenic disorders and violence. Using qualitative research methodology the paper explored the impact of extra-and intrafamilial violence committed by individuals with schizophrenic disorders on their family members' mental health and familial relationships. Part Three comprises a critical appraisal reflecting on the process of the research. Methodological limitations and challenges in conducting the research were discussed in the context of how the results of the research could be used clinically and built upon in future research.

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# PART ONE: LITERATURE REVIEW

Family members as victims of violence from individuals with schizophrenic disorders: why are they targets and what are the consequences?

#### ABSTRACT

This review paper investigated the effects of violence by people with mental health problems. It briefly considered the link between mental illness and violence, before reviewing the literature on the targets of violence from people with mental health problems, concurrently addressing methodological limitations. Family members and/or caregivers are often the victims of violent behaviour from individuals with mental health problems. The effects of this violence were reviewed, integrating findings from the literature on the effects of violent crime on individuals, the effects of domestic violence and the family burden literature. The conclusions drawn referred to the likely individual mental health needs of intrafamilial victims of violence and the possible impact of violence on ongoing familial relationships, whilst highlighting recommendations for future research.

#### **INTRODUCTION**

Violence is a part of human society. Some violence is deemed to be more acceptable and perhaps even necessary, while other violent acts are seen as undesirable and illegal. Blackburn (1993) defines violence as "the forceful infliction of physical injury" (p. 210). Other definitions include the element of intent, whereby aggression necessitates the intent to harm the victim and the expectation that the intended effect will occur (e.g. Geen, 2001). Whilst the former of these definitions focuses on physical injury as the outcome of violence the latter uses the term harm. Harm includes physical injury sustained to the body but also, importantly psychological harm resulting from violence including verbal aggression and emotional abuse. Most definitions of violence also now distinguish between instrumental and expressive violence, the former being when violence is premeditated and used to achieve an obtained goal and the latter being a more reactive or impulsive violent act. Expressive violence is more likely to be mediated by anger (Berkowitz, 1993), whilst instrumental violence is not thought to be associated with the affective state of anger. From this starting point it is noted that definitions of violence differ greatly in their understanding of both the violent behaviour and the result of the behaviour for the victim. For the purpose of this thesis the terms violence, aggression and violent behaviour will be used to refer to both physical violence and verbal aggression.

Official trend measures, such as the British Crime Survey and police recorded crime statistics, show that the level of violent crime in England and Wales has been relatively stable over the past few years (Nicholas, Kershaw & Walker, 2007). In 2006/07 violent crime comprised around one fifth of all crimes committed. Most

serious violence, which includes homicide, attempted murder and more serious wounding, accounted for 0.4 per cent of all police recorded crime.

Although they comprise a relatively small part of overall crime, violent crimes have particularly devastating effects on victims and their families. As a society we invest resources into trying to understand the causes and effects of illegal violent behaviour with the aim of reducing and ultimately preventing violent crime. There are a number of theories of violent or aggressive behaviour (Blackburn, 1993). Historically, biological explanations of violence proposed that such behaviour is under the control of innate and specific neurochemical systems. More recently, such explanations consider the role of anger, on the assumption that anger has a biological basis and mediates aggression. Linked to this, but focussing more on the psychological experience of aggression, psychodynamic theories, such as Freud (1930), assume that aggression is an instinctive human drive; that individuals will behave violently unless they learn to control their urges to do so over the course of their development. Alternatively, social learning theories attribute environmental factors in a causal role, with aggression seen as a behaviour that has been acquired and maintained via the behavioural principles of reinforcement and punishment. Finally, social psychological theories integrate social influences on aggression, such as status display (e.g. Wilson & Daly, 1985) and cultural norms, with individual factors such as personality, in order to explain why some individuals behave violently.

Developmental theories tend to emphasise how and when antisocial behaviour, including violent behaviour, begins, how it is maintained and, if applicable, how it desists. Moffitt (1993) noted the empirical observation that age and antisocial

behaviour share a robust relationship, in that the majority of people who engage in such behaviour do so during adolescence while only the hardened few start prior to adolescence and continue them long after. In constructing this model she developed a strong argument for the increased likelihood of an individual behaving violently being due to a combination of biological factors and social circumstances in childhood. These developmental theories suggest that violent behaviour is not the result of any one specific factor. Instead, the likelihood of an individual behaving violently is based on a complex interaction of a large and varied number of risk factors.

There has been intense social and academic debate over the years as to whether mental illness is one of these risk factors for violence. This paper starts with an overview of recent evidence on the link between mental illness and violence. It will subsequently consider the literature on the targets of violence from individuals with psychosis and the effects of this violence on victims. Links will then be made with the family burden literature with the aim of identifying the effects of being a victim of violence from a relative with psychosis.

#### The link between mental illness and violence

Opinion on the risk of violence posed by individuals with mental illness has varied considerably over the years, with a notable and well documented difference of opinion between scientific findings and societal perceptions. Mental health care provision in the United Kingdom has changed over the last 60 years, with a shift away from institutional care to community care. With this shift there appears to have been an increased prevalence of the belief that individuals with mental illness are at greater risk of violent behaviour than those without mental illness (Link & Stueve, 1998).

Taylor and Gunn (1999) investigated whether the rate of homicide had increased following the move to a community care model of psychiatric services. They concluded that 11% of murders were committed by individuals with a major mental illness, a figure that had not increased as a result of deinstitutionalisation. These murder victims also tended to be family or friends of the perpetrator, with no evidence to suggest that strangers were increasingly the target of such violence.

Wallace, Mullen and Burgess' (2004) longitudinal study of the rates of criminal offending in schizophrenia found that schizophrenia was a risk factor for offending, and particularly for violent offending. They investigated rates of offending over a 25 year period, taking into account the deinstitutionalisation of services and the increased rates of substance abuse and dual diagnosis in individuals with a diagnosis of schizophrenia. Using a patient cohort from an Australian state, they compared patient offending to a community sample, where convictions were grouped into four categories: violent, property-related, substance-related and sexual. They found that individuals with schizophrenia most commonly committed property-related offences and that six to 11 percent of violence in the community was attributable to individuals with schizophrenia. Given that they found a general increase in offending throughout the community and an increased rate of incarceration over this time, the authors concluded that deinstitutionalisation did not play a causal role in the increased rates of offending in the patient sample. With regard to the role of

substance use in criminal offending, the authors emphasised the fact that having schizophrenia and using substances were not independent variables. Nevertheless they found that schizophrenia was correlated with increased rates of criminal offending, including violent offending, independent of substance abuse.

Finally Wallace et al. (2004) found new evidence to counter previous conclusions that all offending in schizophrenia is related to the presence of active symptoms. They found that they could divide their sample into two groups: those whose offending behaviour had begun in childhood and persisted into adulthood and those who began offending in their 30s or 40s. Wallace et al. (2004) concluded that "the factors that influence the presence of criminal behavior in schizophrenia are unlikely to be confined to the effects of active illness but appear to reflect a complex interaction between the deficits in social, psychological, and brain function that precede, accompany, and follow overt disturbances of mental state." (p. 726)

Mullen's (2006) paper was perhaps the most comprehensive and clinically useful review of evidence for the link between schizophrenia and violence. It considered each factor that had been found to be correlated with having schizophrenia and considered whether that factor confounded or mediated the relationship between schizophrenia and violence. Correlates of schizophrenia and violence can then be considered as vulnerabilities that affect an individual at different stages. For example, developmental difficulties and substance abuse can be thought of as vulnerabilities (or risk factors) that pre-date the onset of symptoms and increase the likelihood of violence post diagnosis. Once schizophrenia has developed, factors such as active symptoms and social dislocation may increase rates of violence:

individuals who were discharged into neighbourhoods with high crime-rates were more likely to offend violently. Finally, vulnerabilities that arise as a result of the illness, including side effects of medication and a loss of social skills, can also increase the risk of violent behaviour.

Mullen (2006) referred to a "two-type model for violence in schizophrenia" which can be used to understand an individual's presentation and to predict risk. Type 1 referred to individuals who did not generally have a history of anti-social behaviour and whose violent behaviour tended to be related to an organised delusional system. Such behaviour was also likely to be post-diagnosis and the victim was typically an acquaintance or carer. Type 2 referred to individuals who had a long history of conduct disorder and anti-social behaviour, including non-violent and violent offences prior to diagnosis. They were more likely to have abused substances prior to diagnosis and tended to have a more disorganised clinical syndrome. This group is comparable to what Moffitt (1993) referred to as "life-course persistent offenders".

In summary, it is now well established that there is a link between mental illness and violence. This link is not necessarily generalised to all mental disorders nor is it consistently stable over time. Rather, certain diagnostic categories or groups of symptoms moderately increase the risk for violence, particularly during an acute episode of the illness. The most substantial evidence base, both in terms of quantity and quality, is for the diagnostic category of schizophrenia and related illnesses. For the sake of conciseness the focus of this paper will be on schizophrenic disorders. Given this established link between schizophrenic disorders and violence, this paper will address the questions of who is most at risk from these individuals and what are

the consequences for those victims. Since there is little research into the effects of violence in the context of mental illness on victims, this paper will draw on findings from the study of crime victims and domestic violence victims.

#### **SEARCH PROCEDURE**

The database PsychINFO from first publication to January 2008 and Google Scholar were searched using the broad range of key terms including "violence", "mental disorders", "mentally-ill offenders", "victims" "caregivers" and "family". This was an over-inclusive strategy but due to the nature of the question it was necessary to manually check studies for suitability. The retrieved research papers included 16 studies considering targets of violence from mentally ill individuals and possible explanations of why these individuals are at most risk. A second search was run, again using a broad range of key terms including "violence", victims", "caregivers", "family", "adjustment" "psychological reactance" and "psychological stress" in a number of combinations. This resulted in a large number of retrieved papers, from which suitable review papers and references from these relevant review articles were identified manually. 13 papers were selected for inclusion in this review on the basis of their methodologically sound and informative conclusions about the experience of victims in a number of areas; crime, domestic violence and family burden in mental illness.

#### VIOLENCE, MENTAL ILLNESS AND VICTIMS

In 2006/07 there were 755 homicides recorded by the police in England and Wales (Nicholas et al., 2007) and Rethink (2006) estimates that around 5% of these homicides would have been committed by an offender who was diagnosed with a mental illness. These statistics put into perspective the risk those with mental illness pose to society as a whole when compared to all perpetrators of violent crime. It is perhaps more useful to consider to whom they pose a risk, rather than their contribution to overall violent crime levels.

#### Targets of violence from people with schizophrenic disorders

There have been eleven studies that have considered the targets of violence from individuals with mental health problems in terms of prevalence rates. Some have even gone on to suggest the likely reasons for these victims being targeted. The majority of these studies have been retrospective, evaluating official records such as health records or agency data in an archival approach to data collection. Binder and McNiel's (1986) study was one of the earliest studies that focused on the targets of violence from people with mental illness, rather than focusing on either the incidence of violence from such people or on the perpetrator's characteristics. They randomly selected 300 patients who were admitted to a locked inpatient facility over a ten year period. Given the sampling method, the patients studied varied in their diagnostic groups, although the majority were diagnosed with a schizophrenic disorder. In total 15% of the sample had assaulted someone within two weeks of admission and 54% of those had assaulted a family member. This study was limited by the relatively

Study	Focus of study	Sample Size	Diagnostic groups included	Methodology	Main Results
Arsenault, Moffitt, Caspi and Taylor (2002)	Longitudinal birth-cohort (21 years) study compared with control group looking at targets of physical violence (co-residents, non- household members or street violence) from young adults with (as yet untreated)	N = 956	Schizophrenia spectrum disorders Alcohol dependent and marijuana dependent disorders	Self-report measures of past-year violence & victim targets Logistic regression used to compare levels of violence across both groups and three types of violence	Higher prevalence & frequency rates of assault against co-residents, non- household members & street violence from sample than control group Schizophrenia-spectrum more likely to victimise co-residents
Binder and McNiel's (1986)	Targets of physical violence from patients held in a locked university based short-term inpatient psychiatric unit including situational and interpersonal factors relating to this violence	N = 300	Schizophrenic disorders, affective disorders, personality disorders, substance abuse disorders and other	Medical records reviewed to assess violence in 2 weeks prior to admission Classification system developed to classify intrafamial and extrafamilial violent patients	15% of total sample had assaulted someone 54% of those had assaulted a family member
Gondolf, Mulvey and Litz (1990)	Characteristics of perpetrators of family and nonfamily physical assaults based on evaluation interviews of patients attending the emergency room of a psychiatric unit	N = 389	Not specified	Interviews transcribed & systematically analysed using a computer system Compared 3 categories of assaultive behaviour	35% of assaults were against family members, 53% against non-family members and 12% against both Violence towards a family more likely if perpetrator was more stable, lived with others and less likely to abuse alcohol
Nestor, Haycock, Doiron, Kelly and Kelly (1995)	Investigated the relationship between lethal violence and psychosis on the basis of symptomatology, neuropsychological functioning and perpetrator-victim relationships.	N = 46	Diagnosed with primarily psychotic disorders	Review of official records in six month period following violent act leading to admission Compared 2 groups divided on severity of violence (murder vs. property-related offences)	Both groups showed similar levels of paranoid delusions and delusional organisation Severely violent group more likely to have delusional beliefs about significant others 91% of murder victims were family members (57% parents)

# Table 1: Summary of studies looking at targets of violence from people with schizophrenic disorders

Study	Focus of study	Sample Size	Diagnostic groups included	Methodology	Main Results
Nordström, Dahlgren and Kullgren (2006)	Investigated factors triggering murder and victim relations including symptomatology	N = 48 (all murders in a national sample)	Schizophrenia	Review of forensic psychiatric evaluations and curt convictions compared across two groups (family victims and other victims)	<ul> <li>83% of perpetrators knew their victim,</li> <li>40% of victims were immediate family members</li> <li>72% of familial murder perpetrators had obvious delusions and/or hallucinations</li> </ul>
Nordström and Kullgren (2003)	Investigated relationship between victim relation and violent crime (all physical), including victim gender and severity of violence	N = 588 (all victims in a national sample)	Schizophrenia	Review of court convictions compared across victim groups (family, network and unacquainted)	Majority of victims unacquainted the offender but violence was less severe Female victims, particularly mothers most likely to be fatally injure
Steadman et al. (1998)	Compared prevalence levels of physical violence between a patient sample and a community sample (measured violence to others every 10 weeks in first year after discharge)	N = 1136 patients (N = 519 in community comparison group)	All mental disorders	Used 3 data sources – official agency records, self-reports & collateral informant reports to Compared diagnostic group, 5 follow-up periods & 2 categories of violence	Official records showed 4.5% compared to 27.5% from all 3 data sources had committed at least one violent act Substance use rather than mental health problems found to be most important factor
Straznickas, McNiel and Binder (1993)	Targets of physical violence from psychiatric patients including features of the family relationships living situation, limit setting, paranoid delusions & substance abuse	N = 581	All mental disorders (30% affective psychosis, 29% schizophrenia)	Review of medical records for diagnosis and violence in two weeks prior to admission	19% behaved violently, 11% of those had assaulted family members Young age, psychotic disorders and living together increased risk of violence towards parents
Vaddadi, Soosai and Gilleard, (1997) & Vaddadi, Gilleard and Fryer, (2002)	Prevalence of verbal and physical abuse faced by relatives of patients admitted during a 6-month period to the acute psychiatric unit who had previously been living with a relative and then at 2-year follow up	N = 101 patients and their relatives	79 patients diagnosed with schizophrenia or schizo-affective disorder	Semi-structured interviews relating to burden conducted with family members and levels of types of abuse were coded Correlates of abuse examined using non-parametric statistics	42% experienced verbal abuse, 22% threatened with violence, 24% hit by relative, 4% serious physical injury Abusive behaviour increased family members emotional distress & experience of burden

Table 1: Summary of studies looking at targets of violence from people with schizophrenic disorders continued

short period in which violent behaviour was measured, as it does not take into account violence more than two weeks before admission.

Gondolf, Mulvey and Litz (1990) evaluated interviews of 389 individuals who attended the emergency room of an American psychiatric hospital in order to identify characteristics of perpetrators of family and nonfamily assaults. Of all the violent assaults their results showed that 35% of assaults were against family members, 53% against non-family members and 12% against both. They found that people who assaulted someone outside of their family were more likely to be male, older, live alone and be unemployed. They were also more likely to abuse alcohol and have made previous suicide attempts. Those individuals who were violent towards a family member were considered to be more stable, in that they lived with others, were more likely to be employed and were less likely to abuse alcohol. The authors concluded that perpetrators of intrafamilial and extrafamilial violence ought to be considered as separate groups in terms of the types of clinical interventions offered and when investigating underlying pathways to violent behaviour.

A limitation of retrospectively reviewing medical records is that it is unlikely to account for all violent incidents perpetrated by an individual. Not all violent behaviour is reported to the police, particularly if it is within the family (Nordström & Kullgren, 2003). These two studies also provided limited or no information about the context in which the violence occurred, thus restricting understanding of the link between mental illness and intrafamilial violence. Although also retrospective in its design, Straznickas, McNiel and Binder's (1993) study considered the nature of the interpersonal context in which the violence occurred. The authors reviewed the

medical records of 581 patients admitted to an American secure unit and found that 11% of those patients had assaulted family members. Younger patients with psychotic disorders were more likely to behave violently towards their parents, particularly if they lived with them.

Steadman et al. (1998) compared levels of violence from mental health patients to levels of violence from a community sample and specifically addressed methodological problems such as limited data sources, lack of contextual information and inclusion criteria biased towards individuals with high base rates of violence. Their results showed that by collecting data from three sources – official agency records, self-reports and reports from collateral informants - the proportion of individuals who had committed at least one violent act was around 27.5%, compared to rates of 4.5% when only considering official records. Substance use, rather than mental health problems, was found to be the most important factor in increasing rates of violence for both the patient and community sample, with a higher proportion of mental health patients abusing substances. Similar to other studies, it seems that substance use cannot be considered as an independent variable; rather it seemed to mediate the relationship between mental illness and violence. They also described violence in terms of the type of violent act committed, the target and the location. In both groups family members and friends were the most frequent victims and home was the most likely location.

A further methodological limitation of the studies described is that they may be subject to a selection bias by relying on already identified patients as their sample. In a prospective study using a birth cohort, Arsenault, Moffitt, Caspi and Taylor (2002) showed that having a schizophrenia-spectrum disorder is a risk factor for violent behaviour and increased prevalence and frequency of violence, particularly towards household members. This study did not, however, show the rates at which individuals with schizophrenia-spectrum disorders were violent towards strangers and known victims as information on the victim–offender relationship was lacking except for the worst violent incidents.

In contrast to the research that used psychiatric patients as its sample, Vaddadi and colleagues used a sample of relatives to look at the extent of abuse towards family caregivers and what factors were associated with abuse. An advantage of this is that it is likely to provide a more detailed account of violent behaviour compared to hospital records, which may only record the incident that led to hospitalisation. Results showed that around half of the relatives of a sample of patients admitted to an acute psychiatric unit had experienced verbal abuse and/or threats, between 22% and 32% had been physically abused and approximately 4% had sustained serious injuries (Vaddadi, Gilleard & Fryer, 2002; Vaddadi, Soosai & Gilleard, 1997). The authors found no relationship between diagnosis and abusive behaviour, but there was evidence of associations between younger age, substance misuse and a poorer pre-morbid relationship and abusive behaviour. For family members, being subjected to abusive behaviour increased the level of emotional distress they experienced and increased their perception of burden.

Overall, findings from these studies suggest that the cases in which violent behaviour from an individual with mental illness has been directed towards a relative or acquaintance ranges from 11% to 54%. The difference in prevalence rates is likely to

be due to methodological differences, particularly in terms of sampling and terminology. For example, some studies were broader in their approach focusing on offending (e.g. Wallace et al., 2004) which included but was not exclusive to violent offending whilst others were narrower focusing on violent behaviour only from the outset (Mullen, 2006). It may also be that the terms crime and offending behaviour only include behaviour which is reported formally. Likewise different studies used different definitions of violence, most focused on physical violence, however some included verbal aggression which is therefore likely to lead to a higher prevalence of violence. Likewise the period over which violent behaviour was measured differed greatly; some studies only included violent behaviour in the two weeks prior to admission and other studies included violence in the year following discharge.

Nevertheless it suggests that in at least half of all cases, mentally ill individuals are likely to be violent towards a stranger. This seems to be somewhat confusing given the general opinion in the literature that family members and close acquaintances are most at risk of violence. Some studies have therefore considered the nature of the perpetrator-victim relationship and related it to other factors such as the severity of the violence and specific symptomatology. Marleau, Millaud and Auclair (2003) noted that whilst parricide (killing a close relative) accounts for less than four percent of resolved murders, it forms 20-30 percent of murders committed by psychotic individuals.

In a Swedish study, Nordström and Kullgren (2003) found that although the majority of victims of violent psychotic offenders were unacquainted with the offender, the violence was usually less severe. Typically, when the violence was more severe,

victims tended to be family members, with an increased likelihood of them being female. They identified mothers as being at most risk of fatal injury. This study is useful as it used a highly inclusive sample, comprising all violent crimes in Sweden committed by individuals over the age of 18 years with diagnosis of schizophrenia, although the authors acknowledged that this may have excluded those who were not referred by the court for forensic evaluation. As with previous studies, it is limited in that it does not include violence that was never brought to court and it focuses on physical violence. The study also excluded female offenders, which is likely to limit the extent to which these results can be generalised. More recently, again in a highly inclusive sample, Nordström, Dahlgren and Kullgren (2006) considered all patients with a diagnosis of schizophrenia who had committed murder. Of the 48 perpetrators 83% knew their victim and 40% were immediate family members.

Nestor, Haycock, Doiron, Kelly and Kelly (1995) looked at differences in the severity of violence perpetrated by patients who were psychotic in relation to their symptomatology, neuropsychological characteristics and their relationship to the victim. The study had a relatively small sample and was again retrospective as it was based on information obtained from the health records of 46 patients in an American secure hospital. They created two groups of patients, based on the seriousness of their crime, although they acknowledged the arbitrariness of this division. Both groups showed similar levels of paranoid delusions and delusional organisation. However the content of the delusions appeared to vary with the seriousness of the violent act and the relationship between the perpetrator and victim. The severely violent group were more likely to have delusional beliefs about significant others, such as family members being replaced by imposters, although the relationship

between delusional targets and criminal victims was not directly investigated. In cases where the violent act was murder, 91% of victims were family members and 57% of those were parents.

Overall these eleven studies show that relatives of individuals with mental illness, and particularly schizophrenic disorders, are at risk of violence, especially if that individual is male, in their twenties and living at home. The risk also appears to be related to the severity of the violence, in that relatives are more likely to be seriously or fatally injured than stranger-victims. Specific symptomatology has been found to increase risk, notably if the content of the psychotic delusions or hallucinations relates to individual family members. These conclusions are drawn with the understanding that most of these studies were retrospective in their design and usually relied on one data source. In one respect they are supported by the evidence from prospective data and collateral data. In another, they merely highlight the problem faced by academics and professional services alike; a substantial proportion of violent behaviour goes unreported.

#### Why are family members likely to be victims?

In addition to prevalence rates, some of these studies considered possible explanations for the increased risk of violence towards family members, albeit usually extrapolated from correlational relationships. Based on the significant association found between the victim of the violence and who the patient was living with at the time of the assault, it has been suggested that accessibility of victims plays a significant role in violence perpetrated by mental health patients (Binder & McNiel, 1986; Nestor et al., 1995). Reid (2004) used the term "victims of convenience" to describe relatives who often care for psychotic relatives and increase the risk of becoming a victim through simply being there. Estroff, Swanson, Lachicotte, Swartz and Bolduc (1998) identified increased living time with the individual and being financially responsible for the individual as risk factors for being a victim of violence. They identified mothers living with adult children who have a diagnosis of schizophrenia and co-morbid substance abuse as being at greatest risk.

However, it is unlikely to be a simple matter of convenience and accessibility. A more complex and dynamic process is likely to be occurring in the relationship between the perpetrator and the victim. One of these processes may be the roles to which family members are assigned or assign to themselves. For example, there is evidence to suggest that if family members have taken a role as a caregiver and within this role are trying to impose limits or set boundaries, such as frustrating their relative's impulses or pushing them to take medication, this may lead to feelings of frustration or indeed paranoia on behalf of the patient and act as a trigger for an assault (Reid, 2004; Rose, 1996; Schene, van Wijngaarden & Koeter, 1998; Straznickas et al., 1993). Arsenault et al. (2002) suggested that more information is needed in relation to the potential role of the victim and that it must not be assumed that any violent behaviour was necessarily unprovoked.

A review of early family burden studies cited guilt, confusion, fear and hostility as possible emotional reactions that arise in families following the diagnosis of a mental illness in one of its members (Rose, 1996). Furthermore a disruption in routines and

limited family opportunities for social integration could result in more negative attitudes towards the mentally ill family member (Maurin & Boyd, 1990). These emotional responses and attitudes may serve to affect interpersonal relationships negatively, increasing the sense of tension within the household and acting as possible triggers for violence (Schene et al. 1998).

Another process may involve the nature of the perpetrator's psychotic syndrome and specific symptomatology (Reid, 2004; Straznickas et al., 1993). Nordström et al. (2006) investigated specific symptoms as possible triggers for the murders. Slightly over half the sample were experiencing delusions and/or hallucinations at the time of the offence. Delusions were thought to play a role in making perpetrators feel angry towards or persecuted by their victim. Hallucinations were typically auditory command hallucinations directing the patient to kill. Occasionally the voice was experienced as the victim's voice. Co-morbid problems, such as substance abuse may also play a role (Nordström et al. 2006; Straznickas et al., 1993). However, as was discussed in the introduction, the complex relationship between psychosis, substance abuse and violence is not yet fully understood.

These studies demonstrate that the reasons for the increased risk of violence from individuals with mental illness towards relatives range from the more simplistic and static factors such as cohabiting and accessibility to more dynamic factors such as deteriorating family relationships in the context of acute symptoms and designation of roles.

#### **Psychological effects of interpersonal violence**

Overall around a third of all violent incidents involve an unknown victim (stranger violence), a third could be labelled as acquaintance violence and around 16 per cent were classified as domestic violence (Nicholas et al., 2007). The effects, both physical and psychological, of being a victim of violence are well documented in the literature. There are extensive areas of research focusing on the effects of child abuse (e.g. Beitchman et al., 1992), the effects of domestic abuse (e.g. Hegadoren, Lasiuk & Coupland, 2006), and the effects of crime (e.g. Kilpatrick & Acierno, 2003). The most widely researched clinical disorder in relation to violence is Post-traumatic Stress Disorder (PTSD). PTSD is a common reaction to experiencing a traumatic event like an assault (Ehlers & Clark, 2000). Lifetime prevalence rates of PTSD range from 1% to 14% according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 2000). Frans, Rimmö, Åberg and Fredrikson (2005) reported that women were twice as likely to develop PTSD, despite men reporting more exposure to trauma. The highest PTSD risk was associated with traumas where the interpersonal element was higher, such as sexual and physical assault, robbery and multiple trauma experiences. Other possible symptomatic responses to violence are acute stress disorder, anxiety and depressive disorders and substance abuse (Bisson & Shepherd, 1995). Furthermore, psychological reactions to violent crime can affect people's ability to function on personal, social and occupational levels.

As was concluded earlier, around half of the victims of violence perpetrated by people with mental illness will be family members; however there is very little research focussing on the effects of such violence for this group. For stranger-victims of violence from individuals with mental illness it is likely that the effects will be similar to those of general victims of crime where the perpetrator was not mentally ill. This review will therefore attempt to draw together findings from several areas; psychological distress and emotional adjustment in victims of stranger violence and in victims of domestic abuse, and distress as a result of a relative's aggressive behaviour, as discussed in the family burden literature.

#### The study of crime victims

In their review paper of epidemiological estimates of criminal victimisation Kilpatrick and Acierno (2003) drew several conclusions on the outcomes of victimisation that are potentially relevant to this review. They reviewed evidence to suggest that women were more likely to be victims of violence from individuals known to them and men were more likely to be assaulted by strangers. They found that the relationship between mental health problems and physical violence was strong, however they emphasised that the direction of this relationship is less well established. They cited rates of PTSD in response to physical assault range as ranging from 23 to 39% and they discussed the overlap in diagnostic criteria between PTSD and depression.

Freedy, Resnick, Kilpatrick, Dansky and Tidwell (1994) investigated psychological adjustment in crime victims via structured telephone interviews. They recruited 309 participants using information from legal courts and government departments. Half of their sample were direct victims and half were family members of victims. They focussed on some specific variables; crime characteristics, perceptions of criminal justice system and PTSD symptoms. They found that the relationship between crime type and PTSD was strongest for violent and sexual crimes for direct victims. It should be noted that there was a possible selection bias towards more severe interpersonal crimes as participants were recruited through the courts and it tended to be these types of cases that were resolved by a judicial process. Victims who experienced physical injury or who feared death or physical injury were more at risk of developing PTSD. The authors also found that PTSD was a risk for indirect victims where a family member was murdered. In addition to PTSD, psychological changes that might occur after the murder of a significant other include five stages of grief, overwhelming feelings of rage towards the perpetrator and a release of this rage, often through revenge fantasies (Strang, McNeil & Wright, 1989).

Although Freedy et al. (1994) found evidence to suggest a link between PTSD and violent crime there were a number of methodological limitations that must be considered. The study was retrospective and cross-sectional in its design, which does not control for memory biases or allow for causal attributions to be made. The authors did not measure or control for other mental health problems and previous traumatic experiences, which are both known to be associated with development of PTSD (Brewin, Andrews & Valentine, 2000). Finally the research was conducted by a national survey research firm (i.e. not clinicians), which on the one hand may prevent interviewer bias, but on the other means it relies totally on the quantitative data being taken at face value.

In a similar study, but focussing specifically on physical assault victims, Johansen, Wahl, Eilertsen, Hanestad and Weisaeth (2006) investigated PTSD symptoms, peritraumatic dissociative experiences and anxiety and depression symptoms in a Norwegian sample of 138 participants. Data were collected from people accessing emergency units or reporting a crime to the police using validated quantitative measures. In addition, victims' perceptions of life threat and threat of severe physical injury were assessed via a semi-structured interview. Results showed high prevalence rates of PTSD and 44% of the participants in this study scored as cases with probable anxiety and depression. The authors point out, however, that there is some crossover in the symptomatology and theoretical understanding of anxiety and depression, in so much as their current classification as distinct disorders is under question.

In a prospective study, Brewin, Andrews, Rose and Kirk (1999) looked at manifestation of acute stress and PTSD in victims of violent crime. Their sample comprised 157 people (118 men and 39 women) who had experienced a violent assault from a stranger. Participants were interviewed via telephone at two time periods after the assault. The authors were interested in investigating whether a diagnosis of acute stress disorder at one month after the crime could predict development of PTSD six months later. The results suggested that a diagnosis of acute stress disorder and high levels of re-experiencing or arousal symptoms could be used to predict whether an individual was likely to develop PTSD. The main limitation of the study was that it relied on items adapted from the PTSD symptom scale being used to assess acute stress disorder as no scale existed with established reliability and validity at that time. To address this, the authors tried to align these items with DSM-IV criterion (American Psychiatric Association, 2000) and items from the Impact of Events Scale, which seemed to demonstrate that it was measuring a qualitatively distinct disorder.

#### The study of domestic violence victims

Alongside the literature focussing on victims of stranger-violence, there is a vast area of literature focussing on the effects of domestic violence. It was deemed pertinent to consider some of the general findings from this research because they may be relevant to consequences of intrafamilial violence in the context of mental illness. Most review papers considered the psychological effects of domestic violence on children, with very few looking specifically at the psychological effects of domestic violence for adult victims. Perhaps one of the only studies directly comparing victims of domestic violence and stranger violence is that of Riggs, Kilpatrick and Resnick (1992). With a total sample of 143 women, they had four victim groups where women were victims of marital rape, stranger rape, marital assault and other assault and one group who had no history of victimisation. Using a structured interview, symptom checklists and the Impact of Events Scale, the authors found that all four victim groups showed higher levels of psychological distress when compared to the non-victimised group.

The second in a series of three papers, Holtzworth-Munroe, Smutzler and Sandin's (1997) review article of psychological effects on women of violence from a husband or male partner, discussed mental health difficulties as well as life skills deficits. The paper provided a comprehensive review of studies investigating rates of PTSD, depression and low self-esteem problems in female victims of domestic abuse. The

conclusion drawn was that one- to two-thirds of victims suffered problems of these types and that these problems were positively correlated with the severity and chronicity of the abuse.

Using a systematic research synthesis method Jones, Hughes and Unterstaller (2001) reviewed PTSD symptoms in battered women. This methodology constituted a structured way of reviewing studies in a way similar to that of meta-analysis and traditional literature review. Their review was comprehensive in that it accessed a large number of databases and only included studies that were deemed to be scientifically sound using their coding system. The final pool of studies comprised 43 studies conducted in the past 10 years on PTSD and domestic violence. The general conclusions drawn were that psychological symptoms displayed by victimised women were consistent with major indicators of PTSD (31-84%). Furthermore, the intensity of the PTSD was associated with the extent, severity and type of abuse. In addition to PTSD, depression and dysthymia were found to be associated with abuse. Finally it was established that psychological abuse may be as damaging as physical violence in terms of the psychological distress it causes victims. Despite their own methodologically sound starting point, the authors acknowledged potential problems in the methodology of individual studies. The samples from individual studies tended to be small, non-random and drawn from the same population site. Studies tended to be retrospective and rarely included a comparison group. Finally, overall there tended to be little agreement over definitions of violence and psychological distress, thus making potential problems for comparison.

#### Summary of the effects of interpersonal violence

In summary, the study of crime victims suggests that between a quarter and a third of victims will experience mental health problems, such as PTSD, depression and anxiety. Indirect victims, such as family members of a murdered victim, are also at risk of developing PTSD. The study of domestic violence demonstrates that intrafamilial violence, particularly partner violence has similar psychological consequences for its victims.

One review paper has attempted, using meta-analysis, to draw some general conclusions about the effects of interpersonal violence on psychological well-being. The study included 50 published and pre-publication empirical studies between 1980 and 1992 (Weaver & Clum, 1995). Their inclusion criteria were relatively broad; studies had to be quantitative in their design and focussing on the relationship between interpersonal violence and psychological distress. The included studies investigated the psychological effects of being a victim of childhood sexual and physical abuse, rape, criminal assault and partner physical abuse. The authors reported that since methodological variations were not related to psychological distress did not result from methodological flaws in the included studies.

A statistically and practically significant composite effect size of .24 for the association between interpersonal violence and psychological distress was found suggesting that victims of violence experience significant distress following their experience. Weaver and Clum (1995) proposed that dissociative symptoms and

disturbances in intrapersonal and interpersonal processes were the most prevalent response patterns. They also found evidence to suggest that psychological distress following interpersonal violence was more associated with subjective factors, such as general appraisal, self-blame and perceived life threat, than with objective factors, such as physical injury, force and use of a weapon.

Many of the studies included in this meta-analysis used diagnostic based outcome measures, for example for PTSD, depression, borderline personality disorder and for dissociative disorder. The authors discussed the utility of using crisis-focussed measures of psychological distress compared to measures that consider the longerterm effects of interpersonal violence. However they did not consider more individualised responses to violence, which may not reach a clinical level for a diagnosis of a mental disorder but which nonetheless might cause the victim considerable distress and problems within daily functioning. Finally, the authors acknowledged that there was a high percentage of females in the sample and that this was significantly related to the magnitude of the effect size estimate. They reasoned that this reflected evidence that females are often more likely to be victims of interpersonal violence, especially domestic violence. Given the evidence for mothers being particularly at risk of violence from their psychotic children, it seems judicious to conclude that the results of this meta-analysis are particularly pertinent to this review.

#### Intrafamilial violence and schizophrenic disorders

Relatives' experiences of violence have tended to be included in the family burden literature. In the context of mental illness, family burden is a term used to consider the physical, psychological and social effects of caring for a relative with mental illness (Maurin & Boyd, 1990). Whereas the domestic violence and crime victim literature often refers to consequences in terms of psychological symptomatology and diagnosable disorders, the family burden literature draws on stress models and talks about consequences in terms of objective and subjective burden. The former refers to the negative effects of caregiving demands on family members and the household (Hoenig & Hamilton, 1966, cited in Baronet, 1999). The latter refers to family members' perceptions of the burden. The family burden literature arose after the process of deinstitutionalisation shifted much of the caregiving burden onto families. It was an effort to understand the effects of mental illness on the family in contrast to research looking at how families affect development of mental illness (Rose, 1996). In addition to highlighting situational factors that serve to increase the risk of violence within the family, the family burden literature draws attention to the ways in which fear and expectations of violence can also negatively affect families (Maurin & Boyd, 1990).

In a review of the literature on factors associated with caregiver burden in mental illness Baronet (1999) found that more objective burden was experienced in relation to caregiving tasks such as housework and cooking, providing supervision and transportation. In contrast more subjective burden was experienced as a result of overtly disruptive and aggressive behaviours. Swan and Lavitt (1988) investigated

how families adjusted to living with relatives with a diagnosis of mental disorder who were potentially violent. They found that most families' interactive behaviour was characterised by patterns of tension, fear and anger. Family members tried not to disagree with or confront their relative and if the relative was threatening they tended to leave the situation. This tended to restrict their own lives and reduce their quality of life because they felt the need to provide ongoing care and supervision.

Aside from the inclusion of violence in family burden research, there is no focussed research on the effects of violence on familial victims from psychotic relatives. This may be due to the relatively small nature of this population group not having warranted in-depth investigation as yet. Alternatively it may be indicative of attitudes towards mental illness and violence within the family, where family members and outsiders alike are reluctant to characterise the violence as criminal or even significant and instead view it as an accepted part of caregiving.

The latter explanation is supported by the literature. In looking at help-seeking decisions by victims of violent crime Kaukinen (2002) highlighted a pertinent question in research on violent behaviour; the role of the victim-offender relationship and how it affects perceptions of the severity and criminality of violence. Kaukinen drew on sociological and feminist perspectives of crime to suggest that crimes between people who know each other are often viewed as less serious than crimes between strangers. Approximately only 45 per cent of violent crime gets reported (Nicholas et al., 2007), and Kaukinen suggested that perhaps it is violent crimes between family members and people who know each other that go largely unreported or undetected. Riggs et al. (1992) suggested that research can compound this

problem by failing to compare victims of domestic violence with victims of stranger violence.

### DISCUSSION

The research discussed demonstrates that family members are at increased risk of being a victim of violence perpetrated by a relative with mental health problems. From these studies the risk of being a victim appeared to range from 11% to 54%. The differing prevalence levels can be accounted for by differences in the inclusion criteria and terminology and methodology used. Some studies included all mental disorders and found that schizophrenic disorders tended to be most associated with violence whilst others focussed specifically on schizophrenic disorders from the outset. Physical violence tended to be the primary focus of most studies, however a few studies (e.g. Vaddadi, Gilleard & Fryer, 2002; Vaddadi, Soosai & Gilleard, 1997) also included verbal aggression. The majority of studies were retrospective using archival design methods which investigated the prevalence of violence over differing periods of time, for example two weeks prior to admission or up to a year post-discharge. A number of reasons ranging from accessibility to confrontational interpersonal relationships were suggested for why family members are more at risk than the general public. Individuals with mental health problems do behave violently towards strangers; however the purpose of this review was to consider the effects on victims of intrafamilial violence, as the victims of stranger-violence have been addressed elsewhere (e.g. Kilpatrick & Acierno, 2003).

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There has been little research focussing specifically on the effects of intrafamilial violence in the context of mental health problems; however by considering three distinct areas of research it is possible to draw a number of tentative conclusions. The study of crime victims has demonstrated that potential outcomes from experiencing interpersonal violence include a number of diagnosable disorders. PTSD, depression and anxiety have all been found to be associated with victimisation. The study of domestic violence victims suggests that similar symptom patterns are evident in those who have experienced violence at the hands of a relative, in addition to arguably more pervasive and less symptomatic factors such as low self-esteem and problems with interpersonal relationships. The study of family burden in relation to mental illness suggests that violence can become part of an ongoing relationship in which one relative is providing care to another. Violence is seen as a disruptive and possibly tolerable behaviour within this relationship which adds to stress and burden, but does not necessarily amount to victimisation. This seems to be almost contradictory; on the one hand being a victim of violence is seen as having potentially serious and damaging consequences and on the other it is effectively minimised.

One potentially dangerous effect of this apparent minimisation is that it affects helpseeking behaviour. Many victims seek help from informal networks such as friends and family rather than the police and other professional services. This became more evident when the perpetrator of the violence was known to the victim and the victim was a woman (Kaukinen, 2002). In a study of service utilisation patterns, Horne (2003) found a difference between families who had experienced extra- and intrafamilial violence. Family members of intrafamilial murder victims tended to use services more initially within the first eight weeks and then they tended to withdraw abruptly. The authors suggested that this may be due to feelings of ambivalence towards the perpetrator and such emotions as guilt or shame, which they found too difficult to share outside the family.

Unlike the literature on stranger victims, the domestic violence literature pays attention to the nature of the perpetrator-victim relationship. This acknowledges that violence can be part of complex interpersonal relationship, where causality and temporal sequence cannot necessarily be established. This is not to apportion blame onto victims, or certain victim characteristics (Holtzworth-Munroe et al. 1997), but to acknowledge the interactional nature of a relationship. It seems important to begin to integrate these, as yet distinct, areas of research, particularly the ways in which psychological distress arising from a traumatic situation may manifest in the context of an ongoing relationship. A possible framework for addressing this has already been suggested by Becker-Blease and Freyd (2005) who offer an interesting perspective on the developing relationship between trauma theory and family violence research. Although they focused mostly on physical and sexual child abuse and partner violence, and not violence from a mentally ill relative, the authors highlighted a number of important issues. In addition to the traumatic stressors and outcomes that have been identified within PTSD research, they suggested the need to consider issues such as betrayal, loss of relationships, shame and social isolation.

Another important factor that is apparent both throughout this review and within the three areas of research discussed is the role of gender. In discussion of the prevalence rates and targets of violence from individuals with mental illness it was noted that

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female relatives were often most at risk (Nordström & Kullgren, 2003). Within the PTSD literature it was noted that women are more likely to develop PTSD or other psychological difficulties as a result of being a victim of violence (Frans et al., 2005). Finally, it is noted that the majority of domestic violence literature focuses on women as victims and suggests that they are more likely to be victims of violence from someone they know, which is likely to involve some form of betrayal (Becker-Blease & Freyd, 2005).

## **Clinical Implications**

This review suggests that victims of intrafamilial violence are at risk of developing mental health problems such as post-traumatic stress disorder, depression and other anxiety disorders. In addition to potential physical injuries sustained following a violent assault, victims are at risk of developing emotional difficulties relating to the fear of their life being threatened, anger towards the perpetrator and possible shame. Like any assault victims, victims of intrafamilial violence may therefore require psychological interventions aimed at alleviating their distress and coming to terms with the shock and horror of being assaulted.

However services need to be aware that intrafamilial violence tends to be underreported relative to stranger-violence, as shown by the domestic violence and family burden literature. Families of mentally ill individuals may view violent behaviour as an expected and accepted aspect of the mental illness and therefore not view themselves as victims, thus effectively minimising their own mental health needs.

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Furthermore, intrafamilial violence is likely to have been in the context of interpersonal relationships, thus possibly complicating emotional reactions and making issues of culpability less clear in the eyes of the victim, the perpetrator and indeed the outsider. In addition to individual therapy for victims addressing specific mental health problems, violent behaviour and its impact on the family unit may therefore best be treated using family therapy, provided familial relationships are ongoing. Family therapy has been recommended for individuals with schizophrenia (e.g. Pilling et al., 2002); however its efficacy in preventing and/or treating the consequences of intrafamilial violence has yet to be established.

## **Recommendations for Future Research**

The findings from this review highlight the need for more specific research into the effects of intrafamilial violence in cases where the perpetrator has a mental illness. In addition to identifying the specific mental health needs of these victims, research is needed to address the ways in which violence and its potentially complex emotional reactions – guilt, blame, anger, shame and betrayal – impact on familial relationships. This research could be beneficial in addressing why intrafamilial violence is under-reported and how individuals with schizophrenic disorders and their families are perceived and most effectively treated by mental health services; as family units, individuals, perpetrators or victims.

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# **PART TWO: EMPIRICAL PAPER**

Family members' experiences of schizophrenic disorders and violence

## ABSTRACT

This qualitative, phenomenological study investigated family members' experiences of living with or caring for a relative with a schizophrenic disorder who had behaved violently. Participants were 15 people recruited through patients detained at medium secure units and from a carers' group held at a medium secure unit. They were interviewed using a semi-structured interview format and the interview data were analysed using interpretative phenomenological analysis (IPA). Thirteen themes, grouped into five domains, were extracted. The domains reflected family members' reactions to their relatives' emerging psychosis and violent behaviour, the subsequent process of adaptation and reflection, their involvement in their relatives' recovery and their perceptions of service provision. Family members' accounts were characterised by shock and horror in relation to the violence and a desire to provide ongoing support for their relative. They also revealed a sense of relief following admission to a medium secure unit in the context of having been let down by health care services previously. The findings highlighted the importance of acknowledging the roles and needs of family members in the assessment and treatment of individuals with schizophrenic disorders.

#### INTRODUCTION

The link between schizophrenia and violence is now well established (Mullen, 2006). Indeed, six to 11 percent of violence in the community is attributable to individuals with schizophrenia (Wallace, Mullen & Burgess, 2004). For the families of individuals with schizophrenic disorders, violence is likely to have deleterious effects regardless of whether the violence is targeted within or outside the family. In addressing the ideological debate as to whether the families of violent offenders warrant the label "victim", Howarth and Rock (2000) outlined some of the possible effects of violence on the families of the perpetrator. These included emotional reactions such as shock, disbelief, anger and dismay and the development of mental health problems. For the victims of violence the effect is likely to be significant psychological distress including dissociative symptoms and disturbances in intrapersonal and interpersonal processes (Weaver & Clum, 1995). In addition to personal psychological distress and possible trauma reactions, being a victim of violence from a family member may also adversely affect familial and social relationships (Becker-Blease & Freyd, 2005).

In comparing levels of violence from mental health patients to levels of violence from a community sample, Steadman et al. (1998) found that in both groups family members and friends were the most frequent victims and home was the most likely location. Family members and caregivers of individuals with schizophrenic disorders are at a higher risk of serious violence from these individuals (Estroff, Swanson, Lachicotte, Swartz & Bolduc,1998; Nordström & Kullgren, 2003; Straznickas, McNiel & Binder,1993). It has been found that around half of the relatives of a sample of patients admitted to an acute psychiatric unit had experienced verbal abuse and/or threats, about a quarter to a third had been physically abused and approximately 4% had sustained serious injuries (Vaddadi, Gilleard & Fryer, 2002; Vaddadi, Soosai & Gilleard, 1997). Parents, and especially mothers, are most at risk of violence from their relatives (Estroff et al., 1998). Binder and McNiel (1986) found that 54% of violent inpatients, the majority of whom were diagnosed with a schizophrenic disorder, had assaulted a family member and of those, 34% assaulted a parent, 24% a spouse and 21% a sibling.

There also appears to be a link between the targets of violence from individuals with schizophrenic disorders and the severity of the violence perpetrated (Nordström & Kullgren; 2003). Whilst parricide (killing a close relative) accounts for less than four percent of resolved murders, it forms 20-30 percent of murders committed by psychotic individuals (Marleau, Millaud & Auclair, 2003). In a comprehensive sample of all 48 patients in Sweden with a diagnosis of schizophrenia who had committed murder within a specific time period Nordström, Dahlgren and Kullgren (2006) reported that 83% knew their victim and 40% were immediate family members.

It has been suggested that the accessibility of a victim plays a significant role in violence perpetrated by mental health patients (Binder & McNiel, 1986; Nestor, Haycock, Doiron, Kelly & Kelly, 1995; Straznickas et al., 1993). Risk of violence has been found to increase the longer patients lived with their families, if they were financially dependent on their families and if they had co-morbid substance abuse problems (Estroff et al., 1998). Reid (2004) used the term "victims of convenience"

to describe relatives who often look after psychotic relatives and increase the risk of becoming a victim through simply being there. Adopting a caregiving role and trying to impose limits or set boundaries, such as frustrating their relative's impulses or pushing them to take medication may act as a trigger for an assault (Reid, 2004; Straznickas et al., 1993). Similarly, consideration of the perpetrator's psychotic syndrome and specific symptomatology revealed that delusions may play a role in intrafamilial violence by leaving the perpetrator feeling angry towards or persecuted by their victim and that auditory command hallucinations often directed the patient to kill (Nordström, Dahlgren & Kullgren, 2006).

The effect of this violence on the families has been considered within the family burden literature (e.g. Baronet, 1999; Maurin & Boyd, 1990; Rose, 1996; Vaddadi et al., 2002; Vaddadi et al., 1997). The majority of this research tended to include disruptive behaviours such as possible violence and issues of safety as factors that increased perceptions of subjective burden. The issue of violence towards relatives has been addressed more explicitly by Swan and Lavitt (1988). They investigated the ways in which families adjusted to living with relatives with a diagnosis of mental disorder who were potentially violent. They found that most families' interactive behaviour was characterised by patterns of tension, fear and anger. Families tried not to disagree with or confront their relative and if the relative was threatening they tended to leave the situation. This tended to restrict their own lives because they felt the need to provide ongoing care and supervision and a large majority of people indicated that they would prefer out-of-home living arrangements. In other circumstances family members/caregivers may not be the direct victim of violence, but they may witness and have to cope with the consequences of violent attacks on other family members (Becker-Blease & Freyd, 2005). Even if family members are neither the direct nor indirect victim of their relative's violent behaviour, knowing that their relative has behaved violently towards someone is likely to have affected them psychologically (Howarth & Rock, 2000; Nordström, Kullgren & Dahlgren, 2006). Furthermore if violent behaviour leads to the individual being detained for psychiatric care then there are likely to be ongoing issues for family members and subsequent familial relationships as has been investigated amongst prisoners (La Vigne, Naser, Brooks & Castro, 2005).

The effects on parents of an individual's admission to a secure hospital for violent behaviour have been investigated by Nordström, Kullgren and Dahlgren (2006). They interviewed the parents of 11 men detained for forensic psychiatric treatment in Sweden. Of the 14 participants, one had been the victim of violence by his son. The authors used grounded theory to analyse the interview data. Their analysis revealed four status passages that reflected the experience of all parents; the onset of the mental disorder, the diagnosis of schizophrenia, the violent behaviour/criminality and the recent referral to forensic psychiatric treatment. Within these status passages a number of psychological issues were identified. This study highlighted parents', often mixed, emotional reactions to their son's diagnosis of schizophrenia and subsequent violent behaviour and the impact on the parent-son relationship. Parents reported some negative interactions with mental health professionals and frequently expressed disappointment with psychiatric care prior to the violent offence. This was typically followed by a sense of relief once their son was admitted for forensic

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psychiatric care, incorporating the relief that the schizophrenia has been recognised and the relief that mental health services took over responsibility of care.

The current study built on the findings of Nordström, Kullgren and Dahlgren (2006), focusing exclusively on family members of individuals with a diagnosis of a schizophrenia or schizo-affective disorder to the exclusion of other psychotic disorders but using a British population and extending the sample to include family members other than parents. Furthermore, this study investigated the experience of family members who had been direct or indirect victims of their relative's violent behaviour as well as considering the effects of extrafamilial violence. As family members are frequently the targets of violence, they hold a unique position in being able to offer insight into both perspectives, being a victim of violence and being a caregiver of the perpetrator of that violence. This study aimed to explore the impact this violence had on family members' own mental health and their relationship with the individual and their perception of the responsiveness of services. The goal was to facilitate a better understanding of the needs of families in cases of extra- and intrafamilial violence and improve the provision of services to those affected by violence: perpetrators, victims and families.

The research questions were:

 How do caregivers cope with the after effects of violence, both within and outside the family, by a relative with a psychotic disorder?

- 2) What is the impact of the violence on the subsequent relationship between family members and their detained relative?
- 3) What support do family members need from services?

#### METHOD

# **Participants**

The research took place in two medium secure units (MSU), one based in London (Service A) and the other based in the Home Counties (Service B). Participants were recruited in one of two ways: through relatives detained in either service or through attendance at a carers' support group held at Service A.

For the first recruitment method, patients who had a diagnosis of a schizophreniform disorder and who had behaved violently, either towards a member of their family/caregiver or towards someone outside the family, were identified by a member of the clinical team. Permission was sought from the Responsible Medical Officer (RMO) to approach the patient. Patients were then asked by a member of their clinical team or the psychologist supervising the research for permission to contact their family/caregivers (see Appendices 1 and 2). The researcher approached the family members in writing, explaining the purpose of the study and what would be required of their involvement (see Appendix 3). This was then followed up via telephone by the researcher and family members were given the opportunity to

discuss the research further. If family members agreed to participate an appointment was made to conduct the interview at the MSU (see Appendix 4).

At the time of selection Service A had 100 inpatients. 15 patients were identified by the clinical teams as meeting criteria. Three were not approached due to having unstable mental states at the time of recruitment. 12 patients were approached and 11 declined for a variety of reasons including: not wanting their family "to be bothered", not being in regular contact with their family and not wanting them "to be asked about these things". One patient gave consent for their family members to be approached, however the family member declined to participate, resulting in zero participants from Service A.

At the time of selection the rehabilitation and pre-discharge wards of Service B had 21 inpatients. Initially 10 participants were identified by the clinical teams as meeting criteria. Nine patients gave consent for their family members to be approached and one declined. Nine family members were therefore invited to participate, all of whom agreed initially, however family difficulties prevented one from participating, resulting in eight participants from Service B.

For the second recruitment method family members/caregivers were approached directly through their attendance at a monthly Carers' Support Group held at Service A. The researcher attended the group on four occasions over a six month period. Five family members were approached, one declined and four agreed to participate. Across both services and including both recruitment methods, 15 of the 30 family members who were identified as eligible were invited to participate and 12 agreed to be interviewed. Table 1 provides information on the 12 participants. Of these 12, nine participants were mothers of detained patients, four were fathers, one was a sister and one was a wife. Three couples chose to be interviewed together. Four of the participants had been living with the patient at the time of the index offence, the rest were in regular contact with their relatives. All patients had a diagnosis of either paranoid schizophrenia or schizoaffective disorder.

Eight of the participants had experienced verbal aggression or physical violence from their relative, four of which comprised the index offence for which the patient had been detained. Two participants had been the direct victim of violence from their relative, one participant had witnessed violence against another family member and one participant was present, although did not witness, violence against another family member. The other four participants never reported the violence formally. The remaining four participants had not experienced violence from their relative; however they were aware of their relative's violent behaviour outside the family, typically the index offence.

## **Ethical Approval**

Ethical approval was obtained from Barnet, Enfield & Haringey Local Research Ethics Committee on 09 July 2007 (see Appendix 5). A substantial amendment allowing a different recruitment method was submitted and approved on 20 November 2007.

Participant No.	Patient demographics	Length of admission to MSU	Participant (relationship to patient)	Participants' age & ethnicity	Index Offence: nature of violence	Any intrafamilial violence	Frequency of current contact
P1	Male, 20s, *	< 1 yr	Father	40s, Black British	Extrafamilial	No	Twice weekly
Р2	Male, 20s, *	> 2yrs	Mother	40s, Black African	Intrafamilial (direct victim)	Verbal aggression & physical violence	Monthly
Р3	Male, 20s, *	<1yr	Mother	50s, Afro-Caribbean	Extrafamilial	No	Twice weekly
P4	Male, 40s, White British	> 2 yrs	Father Mother	60s, White British 60s, White British	Extrafamilial	No	Monthly
Р5	Male, 30s, White British	> 2 yrs	Wife	20s, White British	Intrafamilial (not direct victim)	Threats & physical violence	Daily
Р6	Male, 30s, White British	> 2 yrs	Mother	60s, White British	Extrafamilial	Physical violence	Twice weekly
P7	Male, 20s, White British	> 3 yrs	Father Mother	50s, White British 50s, White British	Extrafamilial	Verbal aggression	Weekly

# Table 1: Patient and participant information

\* Information about ethnicity not available as participant recruited independently of patient

Table 1: Patient and par	cipant information	continued
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Participant No.	Patient demographics	Length of admission to MSU	Participant (relationship to patient)	Participants' age & ethnicity	Index Offence: nature of violence	Any intrafamilial violence	Frequency of current contact
P8	Male, 40s, Mixed Black Caribbean/White British	> 10 yrs	Mother	60s, White British	Extrafamilial	No	Twice weekly
Р9	Male, 30s, White British	> 8 yrs	Father Mother	60s, White British 60s, White British	Extrafamilial	Threats/verbal aggression	Weekly
P10	Male, 20s, *	< lyr	Mother	50s, White British	Intrafamilial (not direct victim)	Verbal aggression & physical violence	Weekly
P11	Male, 20s, White British	> 5yrs	Sister	20s, White British	Extrafamilial	Physical aggression	Fortnightly
P12	Male, 30s, White British	> 3 yrs	Mother	50s, White British	Intrafamilial (direct victim)	Threats/verbal aggression	Weekly

\* Information about ethnicity not available as participant recruited independently of patient

## Semi-structured interviews

The primary aim of the interviews was to obtain a comprehensive account of family members' perceptions of and reactions to their relative's psychotic illness, violent behaviour and detention in a medium secure unit. A semi-structured interview schedule, developed for this research, was used flexibly to guide the interviews (see Appendix 6). The semi-structured interview schedule was constructed with the research questions in mind and based on an understanding of the impact of violence on family members from the family burden literature (e.g. Baronet, 1999) and on victims of violence from the post-traumatic stress disorder literature (e.g. Johansen, Wahl, Eilertsen, Hanestad, & Weisaeth, 2006).

To build rapport participants were first asked to talk about their experiences of the onset of their relative's mental health problems and their role in helping to manage the problems. The interview schedule then covered a number of areas including 1) their emotional and practical reactions to violent behaviour, 2) their perceptions of subsequent detention, including service provision, and 3) the perceived impact of the violence and detention on familial relationships. The interview comprised open-ended questions, allowing participants to talk freely, with prompts from the interviewer only when necessary to encourage elaboration and sometimes to refocus participants.

Interviews were between 30 and 90 minutes in duration, although most lasted for approximately 60 minutes. They took place in confidential meeting rooms situated off the wards at the medium secure units. All interviews were audio-taped and transcribed verbatim with any identifying information removed.

## Qualitative analysis

The interviews were analysed using interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003), a qualitative method of analysis that aims to explore systematically, and in detail, participants' perceptions or experiences. IPA aims to understand the ways in which participants make sense of experiences and to examine the meaning of those experiences by systematically searching for themes across a number of interview transcripts. Its focus is phenomenological and interpretative and it is particularly concerned with participants' emotions and cognitions. At the same time IPA acknowledges the position and influence of the researcher.

The meaning of individuals' experiences is considered essential to the IPA process and as a researcher the aim is to identify and convey the meaning of these experiences from the content of the interviews. By focussing on participants' lifeworlds in which they are struggling to make sense of difficult situations the analysis is looking to answer the main research questions such as the ways in which family members cope with violence from a mentally ill relative and the impact of the violence on their familial relationships.

An idiographic approach, as described by Smith, Jarman and Osborn (1999), was applied where analysis of individual transcripts was used to develop themes for the whole data set. In analysing the data, transcripts were read and re-read a number of times as a way of becoming familiar with the personal meaning and key points of each account. During this process initial ideas were noted on each transcript, using provisional labels taken from participants' expressions (see Appendix 7). The second step of the analysis involved collating these provisional ideas into themes, which were again annotated on each transcript so a preliminary set of themes was produced for each transcript (see Appendix 8). The third step involved looking for similarities amongst the identified themes so that a key set of themes, reflecting the data set as a whole, could be generated (see Appendix 9). The fourth step involved grouping these themes together under five domain headings, providing an over-arching structure and reflecting the participants' experiences of the journey from the onset of a schizophrenic disorder to current detention in an MSU.

## Position of researcher

I am a single, white female in my late twenties and I come from a close family who I have always felt supported by. This research was conducted during my final year of training in clinical psychology. I have an MSc in Forensic Psychology and I have worked in medium secure units for one year as an assistant psychologist and six months as a trainee clinical psychologist, however recruitment did not take place in either of these MSUs. Over this time I worked with patients on an individual basis administering assessments and delivering interventions, mostly using cognitive behavioural therapy (CBT). Although I have experience with a variety of therapeutic approaches, I predominantly use CBT in my work with patients. I am interested in the meaning individuals ascribe to certain events and the emotions they experience. I wanted to extend my understanding of forensic issues by considering the role of the family, particularly the ways in which family members perceive their relative's mental health problems and violent behaviour. I anticipated that family members might struggle with conflicting emotions in relation to the knowledge that their

relative had committed a violent offence. I was curious as to how family members might cope with these experiences and how it would impact on familial relationships.

## **Credibility checks**

This research adhered to the best-practice guidelines for qualitative research stipulated by Elliott, Fischer and Rennie (1999). The processes of data collection and systematic analysis have been made transparent and the position of the researcher, including personal and intellectual biases have been stated (Mays & Pope, 2000; Yardley, 2000). The data were subject to credibility checks such as consensus and auditing of themes by two research supervisors at various stages of the analysis in line with Tindall's (1994) suggestion of 'investigator triangulation'.

In addition to the provided explanations for identified themes, use of deviant case analysis ascertained aspects of the data that contradicted the main themes (Mays & Pope, 2000). The themes were grounded in previous research, including the family burden and victims of violence research and findings from Nordström Kullgren and Dahlgren's (2006) study, as a means of theoretical triangulation (Tindall, 1994). Finally, the relevance of this study was assessed by its contribution to existing knowledge and generalisability was considered (Mays & Pope, 2000).

## RESULTS

Family members' accounts were powerful and vivid descriptions of emotive and often life-changing periods in their lives. The qualitative analysis produced 13 themes, organised into five domains. The first three domains relate to participants' personal experiences of their relatives' illness and behaviour. They provide a longitudinal perspective of their reaction to the development of mental health problems, their reaction to the offence itself, and the period of adaptation and reflection that followed. The fourth domain encompasses family members' contribution to the recovery process and their hopes and concerns for the future. The fifth domain focuses more specifically on participants' perceptions of their relative's current treatment and what they would have wanted from services in the early stages, identified with hindsight.

Domains			Themes		
1.	Adjusting to living with psychosis	1. 2. 3.	Something's not quite right Seeking outside help On edge all the time		
2.	When psychosis leads to violence	4. 5. 6.	Emotional reactions to violence Illness not criminality From prison to medium secure unit		
3.	Impact on the family	7. 8. 9.	Continued suffering Looking for understanding Talking vs. privacy		
4.	Moving On	10. 11.	Helping him recover Future hopes & concerns		
5.	Expectations of Services	12. 13.	Current treatment Looking back - what was needed		

## Table 2: Domains and themes

## Domain 1: Adjusting to living with psychosis

The themes in this domain reflect participants' perceptions of their relative's emerging mental health problems, the effect of the problems on familial relationships and their experiences in seeking help from primary care and mental health services for their relative.

### Theme 1: Something's not quite right

Participants described becoming aware of changes in their relative's behaviour, such as becoming increasingly withdrawn and isolative, having strange ideas and decreasing personal care. This was often confusing for family members as, with the exception of one participant, they had no experience of mental health problems within the family.

"He just went into himself, you know. Wouldn't wash, wouldn't eat. Awful time it was. Absolutely awful." (P8)

Often the strange behaviour was characterised as a kind of personality change, comparing how he was pre-morbidly to what he was like when he was ill.

"I knew that there was something up and he become very withdrawn. He used to be really outgoing." (P11)

Their attempts to understand what was happening at the time meant, for some,

considering substance use as a cause of unusual behaviour

"He was quite unstable when I met him, which I didn't realize, I just thought he was a bit wild and off the rails and he used to just drink a lot, there were no sort of signs of him being bad or you know." (P5)

"He didn't sound his normal self... I'm saying to myself I wonder if he's been smoking." (P3)

For others it meant normalising the behaviour in line with expectations of behaviour

during developmental periods such as puberty. It is with hindsight that these

previously misinterpreted behaviours were identified as being the start of a psychotic

illness.

"He became withdrawn and he'd go up in his room for ages, but then I put that down to puberty because you're always against your parents and one thing and another... but he never come out of it." (P7 Father)

## Theme 2: Seeking outside help

For most participants it reached the stage of deciding that they needed to seek outside help. The majority found it was an unhelpful and hugely frustrating experience. Participants were left with the impression that nothing could be done unless either their relative agreed to participate in treatment or he was at risk of harming himself or someone else. "We went to our GP and said GP said is he violent and we said no he isn't. Well we can't do anything unless he is... Well there's nothing we can do unless he volunteers. So that was a horrendous time for us." (P4 Mother)

This resulted in participants feeling that they were not being listened to and that

services did not want to take any responsibility for their relative.

"But because this sickness don't manifester in spots and lumps and being sick, it's not there. They want to screen it out." (P8)

Participants were left feeling frustrated, upset and alone as they watched their

relative's mental health deteriorate.

"Angry because we got nothing from them, absolutely nothing. It was a blank. You're just bashing your head on a brick wall." (P7 Father)

"I just went home and cried and cried... I thought why can't they, why won't they accept that he has a mental health problem?" (P8)

"I think the main thing you feel is lost because you don't know where to go, you make phone calls to social services and they pass you onto someone else and they pass you onto someone else". (P12)

For some participants who did eventually have contact with mental health services,

the experience was one of going round in circles.

"He was admitted to the mental health unit and from then onwards it was quite a nightmare really because he was would get a bit better, then they would chuck him out in the community again before he was well enough" (P11)

# Theme 3: On edge all the time

As participants were often left unsupported to cope with their relative's illness, this frequently meant increasingly difficult familial relationships characterised by hostility and wariness. Around half of the participants described both being a source of frustration to their relative and being a part of their relative's delusional ideation.

"He's waiting for me just to say one thing, one word, do something for yourself, look after yourself..." (P2)

"He thought I was going to poison him. I was getting short-tempered with him because I tried to reason with him and he wouldn't reason." (P8)

"He didn't talk to me because he thought I was part of it. He looked at me once and said don't ask me what's going to happen, you know, you're part of it. Awful, really awful. Very frightening." (P9 Mother)

"However much you say to them, look it's obvious you've got a problem, it's not obvious to them and all you're doing is piling on the nastiness" (P12)

Some participants, despite the increased tension within the relationship and the threat

of violence, described trusting that their relative would not physically attack them.

"Well when he's been really angry and he's directed it at me that, you know, that sometimes can be quite frightening but then at the back of my mind I never thought he would really hurt me...I always felt that thing that was there you know, the mother/son thing, that's just how I felt, that's what stopped him." (P6)

However, these hostile interactions led to physical violence against five of the

participants.

"He did hit me on a couple of occasions. Actually I reached the point where I didn't want to be alone with him because he was so far gone into his fantasy, his psychosis. It was very frightening." (P10)

For a few participants there was also fear that their relative would harm themselves and this left them in a permanent state of expecting bad news.

"Every time, when [husband] went out, someone knocked on the door, I didn't want to go. If the phone went, I didn't want to go because I thought it's gonna be a policeman or it's gonna be someone that's telling me that something's happened." (P9 Mother)

In over half of the families living arrangements were affected. Two of the participants were so afraid they did not feel safe in their own house, two participants asked their sons to leave and three participants described their sons choosing to leave home.

"I had to leave him at home... for my own safety." (P2)

"He left home because he couldn't stand me nagging." (P8)

## Domain 2: When psychosis leads to violence

This domain encompasses participants' reactions to the incidents that led to relatives' admission to a medium secure unit (MSU). This included their beliefs about illness and criminal intention and their experiences of the reaction of authorities; from the point of arrest, via incarceration in prison to the recognition of the need for mental health treatment.

## Theme 4: Emotional reactions to violence

Participants described a mixture of reactions and emotions to their relative's violent behaviour. Two participants chose not to talk about what happened, describing it as *"too painful" (P1).* Around a third of participants were not surprised that something had happened, but expressed shock at the gravity of the violent behaviour.

"But I think because of the build up, because it's been going on for so many years I almost think it didn't surprise us... the severity of it, that was the shock." (P6)

Over half of the participants described feelings of shock and horror in relation to the violence. Witnessing violence appeared to cause more shock and trauma-type reactions amongst participants.

"Total, total nightmare. It was like being in a nightmare... for us it was unbelievably traumatic." (P10)

"It was horrendous, just everything going through your head, it was just so frightening... Oh my god. What am I married to? What the hell am I going to do? How the hell am I going to explain this to my family?" (P5)

(P12) described feeling "dumbstruck" on hearing that her son was threatening to kill her, whilst (P2) struggled with the fact that her son could have killed her. She wanted to distance herself from her son.

"I told them I don't want to hear anything, I don't want to sign anything... I said even I don't want to go to the court. (P2)

Where the violence was extrafamilial the horror appeared to relate to the extent of their relative's illness, whether he might have come to harm and the potential consequences for the victims.

"Horror really. Absolute horror that he was so ill. We didn't know what he'd done, really done. It had said on the news that he had attacked two people. Our full concern was if they were badly injured." (P4 Mother)

Two participants described their thoughts moving from horror about what had happened and concern for their son to the ways in which it would impact on them, including feelings of shame.

"At one point when we thought well if he's flipped like this and we were giving, particularly me, lots and lots of information to the police about him... You suddenly think all the wrong things... Will we actually have to move if he's so angry with us?" (P4 Mother)

"You do feel this shame." (P9 Mother) which was described as "selfish thoughts" (P9 Father).

# Theme 5: Illness not criminality

All participants except one expressed their belief that any violent behaviour was out

of character, due to the mental health problems and totally lacking in criminal intent.

"He's not a criminal he's just somebody who became very unwell and didn't know what he was doing." (P1)

"My son isn't devious. He's a very loving, caring person. He would never do that to anyone if he's in his right frame of mind." (P3)

"He's really not well and I knew he wasn't and although I hated what he did... I knew that wasn't my brother who punched me. It was someone different." (P11)

Some participants also felt it was their duty to inform the police about their relative's mental health problems.

"I said [to the police] one of the most important features of all is that he is schizophrenic." (P4 Mother)

"...to make [the police] aware that's there more than just criminal intent." (P7 Father)

One participant only agreed to make a statement against her son on the basis that he would have a psychiatric assessment and was left feeling infuriated when this did not happen.

"The police lied. Lied! I would not have signed a statement or said anything because I knew he didn't need prison. He needed help." (P12)

In contrast, one participant hinted at the notion of the violent behaviour being a result of "badness" rather than "madness".

"[he] did something bad, he might be that mentally sick, even if you are mentally sick it doesn't mean you are going to be..." (P2)

### Theme 6 - From prison to medium secure unit

Two-thirds of participants explicitly mentioned how difficult it was for them when their relative was detained in prison. Participants disliked seeing their relative in prison and knowing that their mental health problems were still not being treated.

"If he was still in prison I don't know what I would have done, because that would have been much more difficult to cope" (P1)

"I've got a sick son but he's in [prison] ... Initially when he was in prison when we visited it was pretty horrifying. He was still really, really crazy if that's the word." (P10)

Some participants also found the experience of visiting their relative in prison personally mortifying.

"The whole thing was very degrading for us and then when we went in to see him until he started to get treatment it was actually very difficult." (P4 Mother)

"It affected me that he was in prison. It sounds really snobbish but you really are mixing with some very strange people." (P9 Father)

Those families that had spent a long time feeling ignored by secondary services often described a sense of relief once their relative had been admitted to an MSU. This was usually coupled with a sense of horror that such a serious offence had to be committed before their relative's mental health problems were recognised and treated.

"Well horrified it happened but a relief that something has been done now. No way would you want that to have happened to get him into a unit like this but the fact that he is now being looked after and being sorted out, for want of a better phrase... it's... it is a relief." (P6) "So we were relieved actually when he was, I mean it was a horrible thing but it got him there." (P9 Father)

"I know it was a horrible thing to have happened but it was the best thing in a way because he's got the proper care here." (P11)

Two participants expressed relief that they were no longer solely responsible for their

relative, and hence were not in a permanent state of worry.

"But he's safe. Again it comes back to you as well, you can go to work, you can come home and you haven't got that worry." (P9 Mother)

"I think when he came here all of a sudden I just felt like this whole heaviness sort of lifted from my shoulders. Because now they are looking after [brother] properly and I don't have to keep running round making sure he's alive basically." (P11)

Some spoke of their frustration that it had had to get to the stage of such violence

when they had been aware of the risk for long time and were not being listened to.

Their anger towards services and their relief at their son getting treatment was

expressed in the context of horror for the victim and the ways in which his life had

been affected.

"I know it's a bad thing to say but I think it's a bloody good thing he attacked this guy because it's the only way he got bloody help." (P7 Father)

"But you think a lot of it, if they'd have listened could have been averted. The poor bloke that got injured, he's got to live with it for the rest of his life... [son] has done something dreadful, but we feel, or I feel, that [hospital] are also partly to blame." (P7 Mother)

### **Domain 3: Impact on the family**

The third domain incorporates the longer term impact on participants, in terms of ongoing personal suffering, reflection and the coping strategies employed.

### Theme 7: Continued suffering

Following the initial shock and horror of the violent incident, participants appeared to go through a longer period of continued suffering, which in turn affected their health, their ability to work and their finances. Half of the participants described experiencing their own mental health problems, ranging from depression and anxiety to more trauma-type reactions.

"There have been several mornings I can't wake up until 12 o'clock and then I would have flashbacks of what happened on the day of the incident. I tend not to cry much but I'd feel very, very, very depressed." (P1)

"Yeah, it's affected me. Badly... My mind is always thinking of him. I have four hours sleep most nights, wake up in the morning... Sometimes I don't know get through my day (chokes) thinking and thinking and thinking and thinking." (P3)

"Awful. Awful. I had to take anti-depressants, didn't really sleep, had terrible, terrible nightmares that he was going to burst into the house and take me or take [daughter], wake up with hot sweats, it was horrendous." (P5)

The participant who had been attacked by her son also described physical health

problems.

"I'm sick now. I'm feeling like to heal the head and going to where I have to go for several scans. To see whether he has done any brain damage." (P2)

Four participants expressed feelings of anger and bitterness, in one case towards their relative and in other cases towards mental health services.

"I did go through lots of emotions like, you know I felt really bitter towards him, but you know that's gone now; he's a whole lot better now." (P5)

"I get very bitter because it wasn't his fault... if they'd helped him in the beginning he would have had a better life, rather than a locked up life." (P8)

The majority of participants expressed similar sentiments to (P8) about the adverse

impact of the mental health problems and violence on their relative's life.

"Upset for him really that it's taken so much of his life to get to the stage where is now." (P6)

"Disappointed that it happened. It's not what I want my son to be is it, it's not what any mother wants their son to be. But we all get disappointments. (P9F)

"A lot of his friends distanced themselves, because they didn't understand. Then he was on his own really, which was quite heartbreaking to see." (P11)

Three participants referred to their relative's court appearances as being particularly

distressing.

"And I have to be there [court], as much as I know it's gonna hurt so bad. I'm not really looking forward to it... because they are gonna go through all the graphics again." (P3)

"We're a family so do we have to give evidence against each other and that kind of thing... sometimes I think it's going to break us apart totally the family." (P10)

## Theme 8: Looking for understanding

Most participants tried to identify triggers for the psychosis and/or the violent behaviour. All participants, except one, mentioned substance use, mostly cannabis, as a factor in the development or deterioration of their relative's mental health.

"Sometimes I think if he wasn't smoking the cannabis would he have still got schizophrenia or not? You've got all these questions in your head. I do think that probably caused it." (P11)

The majority of participants did not blame themselves or their relatives for what happened.

"We've never blamed ourselves and we've never blamed him." (P9 Father)

Half of the participants were reflective in asking themselves if they could have done anything to prevent it and seemed to be questioning their capabilities as a parent.

"You still blame yourself, what you have done, like the other mother, feel like blaming yourself or asking what could you have done to save him." (P2)

"I think to myself if I didn't do this for him and I didn't give him the kick up the backside... Would it be like this? There's no question to whatever the answers are, so it's just a vicious circle and it's going round and round and round." (P3)

"I think him becoming unwell forced me in a way to examine our relationship. Why did he become unwell? Why did he hate me so much?... I think subconsciously I am responsible for a lot of his problems, feelings of rejection, feelings of emotional neglect." (P12) Another participant went so far as to say she felt guilty and indirectly responsible for her son's violent behaviour. She linked this to her wishes for treatment, expressing a desire to be part of the treatment process.

"I suffer more from guilt actually. I mean I feel that we must have been really poor parents, that's it in a nutshell, for this to have happened... The whole family unit is, I feel, the reason that [son] is in this situation and I think we should be treated as a unit and helped and supported." (P10)

One participant expressed guilt for being more directly responsible, a possible catalyst.

"It wasn't until after he'd done the deed that I thought well I had that bloody argument with him and I went for him. You know, did that tip him?" (P7 Father)

Theme 9: Talking vs. privacy

Amongst participants there were a number of different ways in which talking about

the offence seemed to be important. Half of the participants specifically identified

talking to others as a helpful coping strategy.

"Actually when you talk with somebody, you feel you have taken it out." (P2)

"I have [husband] to talk to and my daughter, is very easy to talk to. She's not so emotional as me, so she's good. And I have a very good friend that I can tell almost anything." (P9 Mother)

"I find it helpful to talk about it. I've always talked about it to my family and my partner." (P11)

In contrast, a third of participants found it difficult to talk to other people, including people within their immediate family. This appeared to be related to a need for privacy and uncertainty about others' reactions.

"I don't really talk much about it within the family at all." (P1)

"It's not because we were ashamed of him doing it, because he's ill. We just don't want to talk to strangers." (P4 Father)

"But I just couldn't tell my mum and dad because I was frightened of them being frightened for me; I was frightened of how they would take it." (P5)

There was a similar split amongst participants in whether they spoke to their relative about the violent incident. A third chose not to, often on the basis that it might be too distressing for all parties.

"I'm very reluctant to go into the incident. I don't do any probing... a) because I think it might be painful for him and it could be painful for me. And b) I kinda leave it to the professionals." (P1)

In contrast a third viewed talking about what happened as an important part of the

recovery process.

"But I think we've come to the point where we have forgiven each other, for the hurt I did to him and the hurt he did to me. I feel that we've reached an equilibrium... By talking through things that happened and why things happened." (P12)

Interestingly, three participants described feelings of disloyalty with regard to talking

about their relative during the research interview.

"I hate talking to you about it as well. I feel like I'm talking about him while he's inside. But I'm not, as he knows, we've talked about it before." (P5)

### **Domain 4: Moving On**

This domain reflects participants' involvement in their relative's recovery process and their thoughts about the future.

### Theme 10: Helping him recover

Nearly all participants described the importance of love and being there for their

relative as a way of helping him to recover.

"We want him to get better and I don't want him in there thinking, you know, nobody cares. If he thinks, what the heck, I don't want a life because nobody cares." (P3)

"I never ever felt that I don't want him for my son. Ever! Not once. I've never stopped loving him, that has not changed at all." (P9 Mother)

For some this was expressed as a part of familial duty.

"We have a responsibility, no matter how old they are, for our children, and as parents it's our duty and our pleasure to help them, in as much as we can. (P4 Mother)

"All I did was, be his wife and stand by him and go up there every day, take him what he wanted, be there for him when all I wanted to do was run away from him really." (P5) "Whether you wanted to or not it really boiled down to that you had to do it because if you didn't he might think that you had abandoned him." (P7 Mother)

In addition to this, the majority of participants explained the ways in which they were also taking a more active role in their relative's recovery. This ranged from reading about schizophrenic disorders in order to offer advice and support to developing an awareness of their relative's triggers for relapse.

"If it was to happen again I looked into it so much more and learnt so much more about the illness and everything so hopefully it would never ever get to that stage again because we'll be so on top of it." (P5)

# Theme 11: Future hopes & concerns

For the majority of participants a significant part of the recovery process appeared to be linked to concepts of "normality". This included the idea of two different people, their relative when they were "well" compared to when they were "unwell". A sense of humour came up frequently as a marker of "normality".

"He does everything quietly and that's the sort of person he was, and is again. So it didn't take much to switch off that aggression." (P4 Father)

"Lovely, I feel like we're getting the old [son] back, his sense of humour is back, he's more affectionate" (P6)

One participant linked this idea of the "well" person to his own ability to cope.

"Well just the belief that [son] was still in there really. You know, he's running round like a lunatic and I have never give up on him. I knew he was in there and this wasn't him." (P7 Father)

For three participants there seemed to be a concern about whether their relative would have been permanently changed by their experience.

*"Whether or not he will be the same sharp, quick, quick witted person I don't know."* (P1)

"So I think it has levelled him out but maybe levelled it to the extent that he's never gonna feel very low or very high... I don't think he'd ever burst out laughing." (P9 Mother)

For these participants the process of recovery meant an improvement in mental health.

Three participants expressed their hopes and concerns in relation to violent behaviour.

"I want him to be well; I don't want him to not be well, to be out there if he's gonna be a menace to society. It's not right." (P3)

"I don't think he's a danger anymore. I think he's reached a point where he knows that he was mad. It's highly unlikely to happen again. If it's at all in his control it's not going to happen again." (P10)

A few participants specifically mentioned their relative's lack of confidence as being

a current concern.

"He needs help with ideas for making a social network, I think that's very important... I see what isolation does and when you have mental health problems you have a lack of confidence." (P12)

Other concerns related to ongoing treatment, discharge plans and future living

arrangements.

"Even now I don't think I can live with him. I can't tell him to take any medication. I can't tell him to shave. I can't even tell him, you are doing the wrong thing." (P2)

"I don't know how it's going to, how exactly it going to work having to have him unbelieve some of the things that he's believed for the last 20 years." (P4 Father)

"I think they need a counsellor with them, for them to go and talk to and get a little bit of guidance and a little bit of kick to say go for this job, do this." (P8)

"We would probably feel easier if he was under more supervision." (P10)

They also reflected issues of institutionalisation and stigma following a lengthy

admission to a mental health unit.

"You can't just airbrush out two, three, four years of your life when you've been in a mental health institution. You know, you can't just say it didn't happen. And then you've got all the stigma that comes with mental health and employment" (P1)

"The future's very worrying. He's not anchored to deal with it. 10 years in any institution. The support needs to be outside. That's what I want to see." (P9 Mother)

# **Domain 5: Expectations of Services**

This domain includes participants' perceptions of mental health services, from

primary care to MSU.

# Theme 12: Current treatment

As was shown by Theme 6 all participants expressed some relief at their relative's admission to an MSU and two thirds of participants expressed satisfaction with their relative's current treatment.

"You just didn't feel he was getting the same treatment [in a private MSU] as, funny enough, as in the NHS. Since he's come here it been unbelievable." (P6)

"Wonderful. Absolutely wonderful. When he was first here and he was still ill you felt he was safe. That was the main thing." (P9 Mother)

One participant expressed a strong desire for the MSU to retain responsibility for her son post-discharge rather than transferring him to secondary services who she viewed as appalling.

"I want him to stay with the [MSU] and if it had come to it I would have sold my house and bought a house nearer here, if I'd had to do that. (P12)

Communication and feeling listened appeared to be an important factor in determining satisfaction with the current treatment. Both ends of the spectrum were expressed.

"I had this problem, especially with communication. Where the psychiatrist is phoning and I think the social worker is phoning. They are not even together." (P2)

"You can ask whatever questions you got. You can voice your concerns and they'll listen to you." (P7 Father).

"They're [the staff] still very, very tolerant and they're still always there to talk. "(P8)

"Communication wise with us with everything, it's been really good. Always made us feel involved with everything." (P11)

# Theme 13: Looking back - what was needed

As part of the reflection process the majority of participants had a clear idea about what would have been most helpful for health services to provide. For those families who had felt ignored by services what they wanted primarily was recognition of their relative's mental health problems.

"He should have been put in a hospital before, or admitted to a hospital before this happened. Something had to be done and it wasn't." (P10)

"He would go up and down and up and down, so they bring someone in when he's down... there was no interview with his family, there was no interview with anyone else connected with him and in half an hour [psychiatrist] wrote off that boy's life and I think it's appalling." (P12)

Two participants clearly stated that they weren't looking to hand over responsibility for their relative; they were merely asking for help in supporting their relative themselves.

"I need to talk to somebody to find out what I can do and he needs to talk to people, just so that I'm not a complete idiot... We wasn't asking them to do it, we were asking them to help us to do it." (P7M)

"I didn't want them to give us anything, all I wanted for them to do was say, oh this poor boy's got mental problems. Let's give him medication that he needs. That's all." (P8)

Linked to this, a few participants mentioned wanting information and leaflets at the time their relative first developed mental health problems as a way to "*signpost people to where the help is available*" (P12).

"A list of places we could phone, that would have been a help because we could have gone places, to find out ourselves. Just for us, not for [son]." (P7M)

Two participants wanted to be able to talk to mental health professionals in confidence so they could "*express views without upsetting*" (P11) their relative.

"I think there are times when you need to talk without the person knowing." (P9 Mother)

Around half of the participants thought that personal counselling would have been

helpful but they seemed to have either found it difficult to access or felt they should

have been strong enough to cope alone.

"I should have really had counselling. I went to the doctors to get some counselling but you've got to fill in a form and then wait six months approximately." (P1)

"It's such a dramatic thing and traumatic, I just have to talk about it and I'm so tearful. I think there should be more support and that side of thing for ones who is going through..." (P3)

"Just to talk to someone. Not trying to hide, deal with it on my own... I'm one of these people that try to put a brave face on everything... but really I'm screaming out for someone to help me really." (P5)

#### DISCUSSION

This qualitative study investigated the experience of family members of individuals with schizophrenic disorders who had behaved violently. The findings showed that family members experienced confusion and a sense of helplessness with regard to the onset of their relative's schizophrenic disorder as shown in the first domain. Family members then appeared to go through a period of intense emotional distress, including shock and horror in relation to the violent behaviour, a period of coping, adaptation and reflection and then a period in which they focussed on their relative's recovery and expressed their hopes and concerns for the future. Family members were also clear in what they had expected and continued to expect from mental health services.

Initially intended as a rapport-building part of the interview, the first domain was in line with findings from other research. The onset of mental health problems was often met with confusion and misinterpretation by families as found by Addington, Coldham, Jones, Ko, and Addington (2003). The process of seeking outside help was described as frustrating by a large proportion of families. Family members felt that they were either not being listened to by health care services at all or, if their relative was offered treatment, multiple, yet brief, admissions were often perceived as being insufficient in managing the schizophrenic disorder (Judge, Perkins, Nieri & Penn, 2005). This typically left families feeling frustrated, unsupported and alone in managing their relative's symptoms including challenging behaviour, which has previously been identified as being a major concern of caregivers (Tennakoon et al., 2000). A sense of powerless and apprehensiveness seemed to pervade descriptions of the period prior to the offence occurring. Familial relationships were often characterised by antagonism and living arrangements were disrupted in line with Schene, van Wijngaarden and Koeter (1998) and Swan and Lavitt (1988). Around half of the family members were targets of verbal aggression including threats or physical violence. This violence was often not reported formally, as found by Nordström, Kullgren and Dahlgren (2006), which may reflect a level of acceptance or even denial of the extent of the violent behaviour on the part of families as has been suggested by Kaukinen (2002).

The other four domains provided a novel understanding of the psychological issues faced by family members of mentally disordered offenders. To some extent these findings were comparable to those reported by Nordström, Kullgren and Dahlgren (2006); however several themes appeared to be more unique to this sample.

Given the years of strange behaviour and strained relationships that often preceded the index offence, most families were unsurprised that a violent incident had occurred but were shocked at the severity of it. For a few families the offence appeared to be more out of the blue. However regardless of expectation, the emotional reactions of family members tended to be shock and horror; shock either that it had got to that stage or that their relative was capable of such violence, and horror about the extent of their relative's illness and the offence itself. Whether the violence was committed within or outside the family appeared to make little difference to family members' emotional reactions. However being present at the time the offence occurred seemed to lead to more intense emotions. This obviously included, but importantly was not exclusive to,

situations of intrafamilial violence. Of interest, very few family members, with one notable exception, viewed themselves as victims. The manifestation of verbal and physical violence did not appear to lead to the designation of perpetrator and victim roles; rather violent behaviour was explained and understood within normal familial roles and within the context of mental illness.

Where violence was committed outside the family there was some acknowledgement of the impact on the victim, expressed empathically for their fear, physical injuries and the feelings of their families. Whilst most immediate reactions related to the likely impact of the violence on their relative or the victim of the violence, a few participants also described the impact on themselves. In situations where the offence was high-profile, family members expressed some feelings of fear and shame about the ways in which it would be reported in the media.

Family members related violent behaviour to mental health problems and some were explicit in their rejection of the term "criminal". There was an understanding that something dreadful had occurred and an acceptance of their relative's responsibility for the violence, but there was little sense of blame towards their relative. In a few cases, family members felt that mental health services should take responsibility for what had happened. These experiences were similar to those reported by Nordström, Kullgren and Dahlgren (2006). Interestingly only one participant expressed anger towards their relative in the belief that he could have done more to prevent the violence occurring. This may be understood by the nature of their relationship, marital rather than family of origin, a relationship that is usually entered into by choice. All

other family members perceived the violence as uncontrollable, again in line with Nordström, Kullgren and Dahlgren (2006).

Perhaps unsurprisingly then, family members viewed incarceration in prison as a particularly difficult period in their history. This was because they found visiting prison personally distressing, they disliked their relative being regarded as a criminal, and were worried about the ongoing lack of recognition and treatment of mental health problems. Following admission to an MSU, family members seemed to experience an overwhelming sense of relief relating to the perceived safety and proper treatment of their relative. As in the Swedish sample (Nordström, Kullgren & Dahlgren, 2006), this was linked to a positive appraisal of the violent behaviour in that it led to more appropriate and effective mental health treatment, which for some at least was a first.

Over the longer-term, participants described ongoing distress that in some cases was suggestive of mental health problems as would be expected given findings from previous research (Tennakoon et al., 2000). Participants described symptoms of depression such as tearfulness, low mood, difficulties sleeping and ruminative thinking, and symptoms of more trauma-type reactions such as nightmares and flashbacks. Use of anti-depressants was described by a few; however most family members tried to cope with these difficulties alone. With hindsight, some family members believed that formal counselling would have been beneficial but at the time found it difficult to access, citing problems with long waiting lists, finding a local service and a general lack of information about accessibility.

Most participants described a process of reflection and self-questioning although they did not tend to blame themselves or their relative. A few were more self-blaming, articulating feelings of guilt about parenting efforts or specific interactions with their relative prior to the offence. Substance use, and particularly cannabis, was implicated in the development of their relative's schizophrenic disorder, a link that has been extensively researched (e.g. van Os et al., 2002), and therefore as playing a role in the violence. Family members also described seeking further information about their relative's diagnosis, for example reading articles and searching on the internet. A quarter of participants seemed to be motivated by their personal experiences to get more involved in mental health services; becoming trust members, working for mental health charities and making official complaints in the hope of preventing similar outcomes for other families.

There was an interesting dichotomy in the ways in which participants viewed talking about the offence and subsequent hospitalisation. Some, mostly female, participants used it as a coping strategy; talking to family and friends or within a carers' support group was seen as having therapeutic benefits and talking to their relative was a way of looking for understanding and preventing relapse. For others talking was seen as more negative; talking outside the family was viewed as a breach of privacy, and for some was possibly shameful, and talking to their relative was avoided for fear it might cause distress for both parties. Male participants, with one exception, seemed to be less likely to use talking as a coping strategy. Gender differences in coping have been addressed extensively in the literature (e.g. Ptacek, Smith & Dodge, 1994). A perceptible aspect of the majority of accounts was the focus on their relative's experience. Although expressed as familial duty or a desire to be supportive, this may also have constituted a personal coping strategy. Likewise recovery for family members was predominantly intertwined with their relative's progress and recovery. Perceptions of a return to normality or to pre-morbid personality functioning were identified as helping family members to cope with what had happened and alleviating their own distress.

There was another apparent dichotomy in family members' perceptions of the future. If the offence had been committed within the last two years, family members tended to focus on immediate future concerns such as court proceedings, length of detainment and how their relative was spending their time. In contrast when the offence had been committed more than two years ago family members were more concerned about their relative's discharge plans, ongoing supervision and reintegration back into society.

Regarding service provision two thirds of family members described feeling let down by primary and secondary health care services prior to the offence, both in acquiring treatment for their relative and in accessing support for themselves. In seeking help they felt lost, unsupported and even ignored. In contrast, the majority of family members expressed satisfaction with the service provided by the MSUs. This was due to their relative being prevented from harming themselves or others, which meant family members no longer felt solely responsible for safeguarding their relative; and also to their relative receiving treatment for the schizophrenic disorder after years of deteriorating mental health. All professions within the multi-disciplinary teams were praised for their role in caring for patients. For those family members who were less effusive in their praise of the MSUs, dissatisfaction related to communication problems with MSU staff and ongoing difficulties in accessing appropriate support for themselves.

#### **Methodological limitations**

IPA was chosen for its focus on the recognition of individuals' distinct experiences and its utility in dealing with sensitive topics, in this case mental health problems and violence . Its key strengths are that it allows for flexibility and openness to multiple interpretative approaches including context, cognition, affect and to a certain extent language. This study attempted to draw together these levels of interpretation to provide a deeper understanding of the meaning of individuals' experiences, from the perspective of the researcher, beyond the content of the interviews. IPA allows the focus to be on a particular group, with detailed claims being made about their experience. It also allows an active discourse with the literature, whereby themes can be related back to existing understanding.

Its weaknesses are that despite the transparency of the researcher's position and the methods of triangulation used to increase validity the analysis process is highly subjective and therefore does not provide a definitive account of participants' experiences. The researcher had some experience of working in medium secure units and was therefore bringing her own level of expertise to the analysis process. Someone with more or less experience, and arguably bias, could interpret the data differently and with so much data to analyse it could potentially be difficult to select a

focus. Theoretically IPA has been criticised for its understanding of the use of language (Willig, 2001). It assumes that people are able to use language in such a way as to capture the subtleties of their psychological experience.

The conclusions from this study should be considered within the context of certain methodological limitations of this research. First, the sensitive nature of the research area led to difficulties in recruiting and a two-stage self-selection process, which in turn resulted in a sample that was biased towards family members who had always been and continued to be loving and supportive towards their relative. It may be that patients and family members who declined to participate experienced more intrafamilial difficulties and were reluctant to participate in research that might have highlighted these difficulties. Similarly those family members who chose to participate often explicitly expressed a desire to tell their story as a means of conveying their dissatisfaction with health care services, whilst those who were more satisfied may have been less eager to participate.

Second, despite opening the recruitment process to all family members, the majority of participants were parents, and indeed mothers. Although this is in line with research suggesting that mothers are most at risk of becoming a victim of violence (Estroff et al., 1998), it means that the views of other family members are not as well represented and understood. Mental health problems and violence appeared to impact differently on marital relationships as compared to family of origin relationships, however given that only one marital relationship was represented it was difficult to draw any conclusions from this study.

#### Clinical implications and recommendations for future research

This study replicates and adds to the findings of Nordström, Kullgren and Dahlgren (2006). Given the somewhat biased sample, the following recommendations are most applicable to cohesive and supportive families of individuals with schizophrenic disorders. Taking more account of family members' views and experiences during the initial assessment phase of a first episode of psychosis may lead to earlier treatment, thus preventing violence. Similarly, given that individuals often decline treatment and families have no previous experience of schizophrenic disorders, treating family members as service users may lead to better outcomes for individuals. Within this sample, family members were looking for better signposting towards information and support so that they could help their relative themselves. Providing psycho-education about psychotic symptoms and enabling families to communicate more effectively with psychotic relatives could reduce the likelihood of hostile interactions within families and thus reduce the risk of physical violence. Including families in the assessment and treatment process is likely to have a contributory effect on individuals' mental health as given the findings of this research, family members often play a significant role in the recovery process and relapse prevention. Good communication with mental health professionals is an effective way of promoting feelings of inclusion and might be achieved through additional staff training.

A number of issues highlighted by this study might warrant further exploration. Given the apparent impact on family members' mental health, a quantitative study assessing the prevalence of specific symptomatology amongst families of detained patients seems essential. It would also be interesting to investigate further the apparent gender and relationship-role differences in coping and understanding.

In terms of psychological interventions, family therapy has often been identified as being an effective treatment approach in schizophrenia with regard to reducing the likelihood of psychotic relapse and readmission and increasing medication compliance (e.g. Pilling et al., 2002) however it has been used relatively infrequently in MSUs (Geelan & Nickford, 1999). In addition to increasing opportunities for family therapy, services need to increase their awareness of the individual psychological needs of family members and provide opportunities for treatment. It is clear that many family members valued talking about their experiences as a coping strategy; some explicitly identified it with hindsight, others referred to the therapeutic benefits of participating in the research interviews. It is for further research and services to investigate whether individual psychological therapy for family members is best provided for by the same service that treats individuals with mental health problems or by a different service.

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PART THREE: CRITICAL APPRAISAL

#### From conceptualisation to recruitment: issues of feasibility

This research was conceptualised in the context of personal experience of having worked as an assistant psychologist and a trainee clinical psychologist in different medium secure units (MSUs) for 18 months. During this time I observed informally the numbers of patients whose index offence and other violent behaviour had been committed against family members. Moreover, subsequent training placements, particularly in child and older adult services, seemed to place more significance on the systems within which individuals operate. Hence I became curious about the tendency in forensic adult services to treat patients as individuals, often to the exclusion of their family units. At that time the MSUs were not offering family therapy and aside from meeting family members at Care Programme Approach meetings (CPAs), I did not have the opportunity to work with families. A literature search revealed that there has been remarkably little research on the effects of intrafamilial violence in the context of mental illness, especially the impact on victims and interpersonal relationships.

The original idea for this research was to focus exclusively on intrafamilial violence in an effort to address a currently under-researched area. However there were difficulties in recruitment due to the necessary two-stage recruitment process. Since victimised family members were being identified through patients' medical records or from members of the patients' clinical team it was ethically necessary to obtain consent from patients prior to approaching their families. Given the sensitive nature of the research questions, it was perhaps not surprising that many patients were reluctant to participate. Intrafamilial violence often occurs in the context of difficult interpersonal relationships (Swan & Lavitt, 1988) and this may have meant that

patients were not in close contact with their families and were therefore less inclined to allow researchers to contact them. There may also have been some concern about perceived familial dysfunction being scrutinised by mental health services. In addition, individuals with schizophrenic disorders often present with paranoid ideation as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 2000) and they might therefore have felt suspicious and concerned about the questions asked of their family members and the potential answers given. It was therefore necessary to expand the inclusion criteria to include extrafamilial violence so that the focus became family members' perceptions of any violence committed by their psychotic relative.

This shift halfway through recruitment partly accounted for the different recruitment rate from Service A as compared to Service B. Initially Service A had focussed exclusively on recruiting patients who had been violent within the family, who were fewer and arguably more difficult to recruit, and by the time Service B was included the inclusion criteria had already been expanded. Another, perhaps more significant, reason for the increased recruitment rate from Service B was that they were already engaged in various forms of family working and the psychologist who was recruiting had established and trusting relationships with patients and their families. Indeed, families often referred to the psychologist by name both whilst considering participating and during the interviews.

At one stage the recruitment policy was also expanded to include the possibility of recruiting family members directly through a carers' group held at one of the MSUs. This raised certain ethical questions, namely whether it breached rules on

confidentiality about patient information. The MSU had previously encountered a similar dilemma when setting up the carers' group; since the demographic information about carers necessary to invite them to a group was accessed via patients' files, should patient consent be sought? The facilitators had decided that carers were a client group in their own right and therefore could be offered a service independently of patients. A substantial amendment was applied for via the ethics committee and granted.

Whilst these changes in the inclusion criteria and recruitment process meant a sample size of 12 was achieved, it was possibly to the detriment of the heterogeneity of the sample. As discussed in the methodological limitations section of the empirical paper, the sample almost exclusively comprised families that were characterised by close and supportive relationships. Families who had been torn apart by psychosis and violence would have been interesting to interview as a contrast to the more supportive families, however it is possible that their negative responses towards the research were linked to their familial relationships having been so adversely affected.

#### Challenges in qualitative interviewing

The decision to investigate this area qualitatively was influenced by the paucity of research into families of violent offenders and my interest in conducting qualitative interviews as a means of gathering data. One challenging aspect of the interviews was accessing family members' own experiences and emotional reactions, particularly when the offence was committed more than three years previously. These participants

had a tendency to recount what appeared to be a well-rehearsed story from the perspective of their relative's experience and often comprising a description of historical events. Hence it was difficult to extract more salient meanings.

There are a number of possible reasons for this; first it may be that since the focus for the study and therefore throughout the interviews was on family members' reactions to mental health problems and violence and since the interviews were conducted within the MSU I may have been seen as a member of the MSU staff, despite my status as an independent researcher. Therefore participants might have felt inclined to focus on their relative's experience as the service user rather than their own experience. This position was presumably one they were used to adopting at CPA meetings and reviews. With a different starting premise it is likely that other complex issues may have become apparent, for example if the mentally ill individuals had not been charged or detained perhaps family members would have been more able to focus on their own experience outside the context of mental health services. Equally, as a comparison, it would have been interesting to interview family members of prisoners where issues of culpability were, perhaps, more clearly assigned to the prisoner.

Second, talking about violence is a difficult process, increasingly so when a relative is the perpetrator of the violence. It may be that their particular method of story-telling allowed them to defend against potential anxieties relating to their experience of the violence (Gadd, 2004).

Third and inextricably linked to the preceding two points, as a relatively inexperienced interviewer my techniques and interactional style would have had considerable impact on the quality of the data gathered. Where participants were inclined to repeat a story that they had built up and ruminated on over the years, it was my task to elicit previously unconsidered aspects and new perceptions of that story. Over the course of data collection I became progressively more reflective in relation to my interviewing style. I was aware that during earlier interviews perhaps I had been hesitant to pursue lines of questioning that I felt were emotionally challenging or might have been perceived as confrontational. As Gadd (2004) described it in his exploration of the dynamics between interviewers and interviewees, "both parties come to the research process as 'defended subjects', and both depend upon this defensiveness for psychological protection during interviews." (p. 398). Moreover, although referring to therapists rather than interviewers, Rober, van Eesbeek and Elliott (2006) suggested something akin to this in their microanalysis of narrative processes in a family therapy session, "the therapist can invite new stories to be told, but he/she can also be hesitant and even silence stories of violence and suffering, just like the other participants in the conversation."

(p. 325).

With family members whose experience of their relative's violence and admission to an MSU was within the last year, accessing emotional information was somewhat easier. However their reflection process and attempts to understand what had happened were less coherent, perhaps due to having had less time in which to process and come to terms with what had happened. Something I had not anticipated was my inclination to interpret and formulate participants' responses as I would in a clinical interview rather than concentrating on their perceptions and understanding. In contrast I noted that I could have used other therapeutic skills more in the research interviews, for example using silence and being less directive to elicit more information and encourage elaboration (Britten, 1995).

#### **Emerging themes and surprising findings**

The process of analysis highlighted difficulties in grouping themes. Identifying relevant themes in such a way that they reflected general findings from participants' accounts may have been at the expense of individual viewpoints. It was difficult to ensure that all participants' views were represented fairly. During the analysis process I was aware that I had a tendency to ascribe more weight to those participants who spoke ardently and articulately about their experiences. Equally challenging was remaining objective and not allowing my own preconceptions to obscure the analysis. As I described earlier some participants presented an apparently coherent and rehearsed narrative during the interviews. This was often at the expense of emotional expression, which gave the – perhaps false – impression of distanced attitudes towards their relatives. At times I struggled with being able to place data collected during a one hour interview in the context of, perhaps, 20 years of family history.

My choice of IPA instead of another qualitative analysis method was because I wanted to understand the psychological experience of my participants, however it

may have compounded the challenges just described. As touched on in the discussion of the empirical paper IPA's theoretical stance on language, in that it treats language as representing inner processes, may have been problematic. Some participants seemed to struggle with describing their emotional experience, perhaps because they lacked the appropriate language, and yet IPA allowed me to make claims about their emotional states and thoughts. This highlights another problem with IPA, its subjectivity; using an alternative analysis would likely have led to different, and perhaps more objective, understanding. For example using grounded theory would have allowed me to examine the more social processes surrounding mental illness and violence whilst focussing less on individuals' experiences.

When conceptualising the research I had anticipated finding a notable difference between family members' experiences of intra- and extrafamilial violence. I had expected families who had experienced intrafamilial violence to struggle more with conflicting emotions, particularly around issues of culpability and anger. Interestingly, despite fearing their relatives, a few participants described a belief that their relative would not be violent towards them. This apparent trust is something that might warrant further explanation as it may be indicative of a particular strength in familial relationships that could be used within family therapy settings to treat schizophrenic disorders. Alternatively it might hint at either avoidance or denial of potential risks, which again could be explored in family therapy as part of relapse prevention. Part of the coping process appeared to involve trying to comprehend why the violent behaviour had occurred in the hope that understanding would help prevention in the future. As noted in the discussion, most family members neither considered themselves to be victims nor their relatives to be offenders. This lack of role and blame designation was contrary to what I had anticipated. An interesting paper by Berns and Schweingruber (2007) on how women make sense of domestic violence suggested that being involved in a social problem makes understanding that problem more challenging. In contrast, those not involved (i.e. the general public, the media) tend to make sense of that problem in more simplistic and definitive ways, often missing the complexities and ambiguities of the interpersonal relationships in which violence has occurred. It may be that, having had no personal experience of schizophrenic disorders and violence within my family I was looking for, and indeed expecting to find, clearer explanations of how familial relationships were affected in these situations.

Linked to this, in the theme *Looking for understanding* one participant acknowledged his own anger and potential violence towards his son and yet did not appear to acknowledge his son's vulnerability. In addition to, and perhaps in response to, the literature on the risks posed by individuals with mental illness there has been some literature on the increased risk of victimisation also experienced by those with mental illness (e.g. Thornicroft 2006). Perhaps in this study it would have been interesting to investigate the potential for aggressive behaviour from the family towards the individual with mental illness to increase the understanding of familial dynamics.

In addition to the sense of relief that family members felt in relation to professional services recognising their relative's mental health problems, there was a more implicit sense of relief that their relative also recognised their own mental health problems.

Insight and its relationship to outcome in mental health treatment have been discussed by Schwartz (1998); this paper hints at the effects of a patient gaining insight on family members. Some family members hinted at their frustrations that their relative had little concept of how the mental health problems impacted upon them. It could be hypothesised that insight allows familial relationships to be re-built following years of perceived persecution and hostility by facilitating bi-directional empathic understanding.

Another interesting aspect of the recovery process identified by family members was the recovery of a sense of humour; it was often cited as being a defining feature of normality. Tsoi et al. (2008) found that individuals with schizophrenia showed a diminished ability to recognise humour but not to appreciate humour. They referred to patients' difficulties in understanding humour that required them to 'mentalise'. In line with this one participant mentioned her relative's tendency to react in a paranoid manner to humour whilst acutely psychotic. It has been suggested that humour is an important aspect of forming and maintaining interpersonal relationships (Martin, 2006). Therefore, perhaps it is unsurprising that family members welcomed its return to their relationships with their relatives. The ways in which humour is perceived and used within familial relationships, particularly its therapeutic benefits might warrant further exploration.

Finally, gender was not an issue I had intended to explore via the research questions; however some gender differences became apparent during analysis. With the exception of one father, the participants who seemed to want and need psychological interventions for themselves were all female. Male participants, in contrast, seemed to focus more on looking for explanations for the schizophrenic disorder and violence, particularly favouring more biological explanations, as a coping strategy. This is in line with research on gender differences in coping strategies, which suggests that women use more emotion-focussed coping including seeking social support and men use relatively more problem-focussed coping strategies (Ptacek, Smith & Dodge, 1994). This study suggested that gender differences in coping strategies were due to different socialisation experiences for men and women dealing with stress. Services would benefit from being aware of these differences, individualising services offered to family members and not assuming that all family members desire talking therapies.

#### Methodological improvements

Limitations of the research were addressed briefly in the discussion section of the empirical paper; however it is worth expanding on those here. The characteristics of the sample were a reflection of the difficulties in recruiting and a product of a self-selection process in recruitment. Nordström, Kullgren and Dahlgren (2006) described similar difficulties in their research, however at least their initial population, from which the sample was drawn, comprised all mentally disordered offenders within Sweden. The current patient sample was best understood in terms of Mullen's (2006) Type 1 group who do not generally have a history of anti-social behaviour and whose violent behaviour tends to be post-diagnosis and related to an organised delusional system. The current participant sample comprised families who maintained positive familial relationships and therefore may have been less psychologically affected than those who declined to participate. Used in conjunction with Nordström, Kullgren and Dahlgren's (2006) findings it may provide a Eurocentric account of how

schizophrenic disorders and violence affect families. However, since the sample excluded non-English speakers, the generalisability of the findings is limited in terms of cultural understandings of mental illness and violence.

The decision to interview parents together in their roles as couples led to some interesting findings about familial relationships and the couple unit as a coping resource. Couples tended to react to each others' contribution to the interview arriving at a joint account of their experiences. However there was typically a dominant member of each couple telling the story and this may have hindered some participants' ability to reflect on more difficult aspects of the parent-son relationship. There was a sense from two fathers in particular that they had distanced themselves from the father-son relationship and their support was directed towards their wives, whilst their wife focussed on, and indeed talked more about, their son. Exploring more negative impacts of schizophrenic disorders and violence on familial relationships would have been interesting, but perhaps not feasible when one member of the couple was expressing unfaltering support.

Despite being qualitative and exploratory in its design, this research could have had a more specific diagnostic focus. Given the numbers of participants describing depressive and trauma-type symptoms it might have been justified to address these issues more directly, exploring in further detail levels of distress and impairments in functioning. Indeed, including self-report measures of distress such as the Beck Depression Inventory II (Beck, Ward, Mendelssohn & Erbaugh; 1961) or the Impact of Events Scale (Horowitz, Wilner & Alvarez; 1979) could have added an interesting quantitative understanding to the qualitative data set as a form of triangulation (Tindall, 1994). In line with earlier observations about differences in emotional expression relating to time since the index offence, it might be hypothesised that family members present with more distress immediately after a violent incident. If this were found to be true, services could be advised to ensure families are offered support and treatment in the aftermath of an offence and an admission to an MSU. Although there appeared to be little difference in how families experienced extra- and intrafamilial violence, Horne (2003) found a difference in their service utilisation patterns. Intrafamilial violence tended to result in immediate and more intense use of services, followed by an abrupt withdrawal, possibly due to feelings of ambivalence towards the perpetrator and emotions such as guilt or shame, which people found too difficult to share outside the family.

#### Additional clinical and scientific implications

Family members' perceptions of, and often strong opinions on, the difference in mental health care services provided by primary or secondary care services and specialist services such as forensic services reflects a common attitude towards mental health services in the United Kingdom. Patients and their families experience repeated hospital admissions as decreasing their personal control and frustrating (George & Howell, 1996), and mental health professionals describe feeling demoralised by "revolving door" patients (Reid et al., 1999). Lamb, Weinberger & DeCuir, Jr. (2002) suggested that better mental health resources could lower the number of hospital admissions and also reduce the likelihood of individuals with mental illness becoming criminalised by a police system who are often left responsible for dealing with mental illness.

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The findings from this study suggested that families viewed MSU treatment as more effective than secondary care as they believed their relative was under more intensive supervision and that the longer admission period allowed more intensive work focussing on social and psychological aspects rather than simply stabilising individuals on medication and discharging them into the community. It is both worrying and meaningful that familial responses to violent behaviour and admission to a secure environment are ones of relief. Whilst acknowledging the recent policy shifts towards preventative services and early intervention it is telling that the quality of service provision is of a much higher standard post- rather than pre-offence.

Finally, an important contradiction was highlighted by this research; family members spoke of their frustration in not being able to access treatment for their relative until he had already been violent and at the same time described violence within the family prior to the offence which was not reported formally. This may be indicative of family members, and society, minimising or denying intrafamilial violence as suggested by Kaukinen (2002). A different approach to research, for example making violence within schizophrenic disorders a research topic in its own right instead of including it as subjective burden within caregiving, may shift attitudes towards intrafamilial violence. If family members were encouraged and listened to when reporting intrafamilial violence, the likelihood of violent behaviour escalating in severity might be reduced.

#### Conclusions

As a complete piece of research, from literature review to empirical investigation, this thesis addressed the role of families within forensic mental health services. It attempted to integrate distinct research areas, including research into the perspectives of victims and research investigating family burden in mental illness, to understand the impact of violence from the perspective of the family. The literature review demonstrated the need for more focussed research and provided the basis for the qualitative investigation of family members' experiences of schizophrenic disorders and violence.

Conducting the research was a remarkable and, at times, challenging experience which has hopefully added to the general understanding of violence within mental illness and has increased my personal awareness of pertinent issues within forensic clinical psychology. Families of mentally disordered offenders were often viewed and treated by MSU staff as mere informants of an individual's life history. Increasing numbers of MSUs are becoming aware of the vital, and often self-sacrificing, role families play in their patients' lives and are beginning to view them as service users warranting support and if necessary, treatment.

A particularly striking aspect of the research was the need and wish people have to tell their story and to be listened to. Those family members who opted to participate seemed to be doing so for two reasons; first in the hope that sharing their experiences would improve service provision and second in anticipation that they would derive some therapeutic benefit from the research interview. Drury, Francis and Chapman (2007) commented on the therapeutic nature of qualitative interviews and how it can be hard to maintain the boundaries of the research when participants become distressed. In setting up the research I had anticipated the possible beneficial and adverse outcomes for participants of discussing potentially traumatic events. I was therefore relieved, as a clinician and a researcher, to discover that the overwhelming response from participants was positive.

Further exploration of this topic area is necessary and justified, particularly for families where the violence and mental illness has led to family breakdown and loss of relationships. Perhaps then this data can be revisited with an enhanced reflexivity that is difficult to achieve when one is so focussed on and invested in specific research questions (Gadd, 2004).

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**APPENDIX 1: Patient information sheet** 

Barnet, Enfield and Haringey



Mental Health NHS Trust

# PATIENT INFORMATION SHEET

Version 2: July 2007

# Family Members' experiences of mental illness and violence

We are doing a study looking at what it's like to live with or care for someone who suffers from mental health problems and who sometimes behaves violently.

We would like to interview your relative about their understanding of your mental health, your violent behaviour and what it was like for them when you were detained in hospital.

It will help us to:

- Understand the impact of mental health problems and violence on someone's family
- Improve our services to help patients and their families cope with the after-effects of violent acts and detainment in hospital

We would like your permission to approach your relative to ask them if they would like to take part in this study. You will not be required to do anything else with regard to this study and anything your relative talks about will be confidential to the researcher and will not be made available to your clinical team.

Please see either a member of your clinical team or Dr Mike Watts, Clinical Psychologist, for further information.

**APPENDIX 2: Patient consent form** 

Barnet, Enfield and Haringey

Mental Health NHS Trust

Centre Number: Study Number: Patient Identification Number for this trial:

# CONSENT FORM

Title of Project: Family members' experiences of mental illness and violence

Name of Researcher: Joanna Barlas

#### Please initial each box

1. I confirm that I have read and understand the information sheet dated...... (version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I agree to the researcher to contacting my relative and asking if they would like to participate in this study.

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Name of Researcher	Date	Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes





**APPENDIX 3: Participant information sheet** 

Barnet, Enfield and Haringey

Mental Health NHS Trust

# PARTICIPANT INFORMATION SHEET

Version 2: November 2007

### Family members' experiences of mental illness and violence

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

#### **Researchers:**

Joanna Barlas, Trainee Clinical Psychologist at UCL Dr Mike Watts, Chartered Clinical Neuropsychologist at Camlet 3, Chase Farm Hospital

Please contact Mike on if you wish to have any questions of if you wish to participate.

#### **Outline of the Study:**

This research study is being undertaken as part of the academic requirements for the chief researcher's doctorate in clinical psychology. It aims to investigate, via interview, your experiences (as a family member or caregiver) of violence by a relative who suffers from mental health problems. It will look at what impact this violence has on yourself, your relationship with the individual and your beliefs about the responsiveness of services. It is hoped that the results of this study can be used to understand the needs of both victims of violence and the families themselves and to improve services for those affected by violence.

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you, or your relative, receives.

#### What is required of you:

If you decide to participate your involvement in the research will be for a one-off interview. The researcher will arrange a convenient time to interview you at *(insert name of medium secure unit)*. You will be met and interviewed by the researcher. On average, the interview will last between 30 and 45 minutes. Before and after the interview you will have an opportunity to ask questions about the research.

Care will be taken to make the interview as comfortable as possible for you. In the event of distress arising, a break will be provided and then you will be given the option to discontinue the interview. A debriefing process will follow the interview and contact numbers for appropriate support services will be made available to you.

You will be reimbursed for your travel expenses to and from *(insert name of medium secure unit)*. You will also be paid £10 a "thank-you" for participating in the interview.

#### Confidentiality

The interview will be recorded and then transcribed. We will follow ethical and legal practice and all information about you will be handled in confidence with any identifying information concealed. All information which is collected during the course of the research will be confidential unless, in the interviewer's judgment, you are at risk of harm to yourself or others. In addition, if you disclose previously unreported criminal acts, it may be necessary to break confidentiality.

The recorded data will be assigned a number for research purposes only and will be stored on the chief-investigator's laptop with no personal information stored with it, so that the data cannot be identified. Direct quotes from your interview data may be used in the research, however these will be anonymised and nothing that could identify you will be used.

Only the researcher and two research supervisors will have access to the data. If you withdraw from the study, we will destroy all your identifiable data and we will not use the data collected up to your withdrawal.

#### Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

#### Harm

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

#### **Results of the Study**

It is hoped that the information we get from this study will help improve the provision of mental health and support services to people like you and your relative.

A written summary of the results of the research will be made available to you upon request. Individual results will not be discussed, other than to direct relatives towards appropriate services if requested.

As well as being submitted as part of an educational qualification it is intended that the results of the study will be published in an academic journal. You will not be identified in either the educational report or the publication.

#### Who is organising and funding the research?

The research is being organised by the chief investigator and funded by University College London as part of an educational requirement.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Barnet, Enfield and Haringey Research Ethics Committee.

#### **Further Information**

If you require further information, please use the following contacts:

- For general information about research please go to: http://www.nres.npsa.nhs.uk/
   For specific information about this research project please contact:
- Dr Mike Watts on 020 8375 2713.
- 3. For advice as to whether you should participate please contact: Your relative's Responsible Medical Officer (RMO)

**APPENDIX 4: Participant consent form** 

Barnet, Enfield and Haringey

Mental Health NHS Trust

Centre Number: Study Number: Patient Identification Number for this trial:

# CONSENT FORM

Title of Project: Family Members' experiences of mental illness and violence

Name of Researcher: Joanna Barlas

#### Please initial each box

1. I confirm that I have read and understand the information sheet dated...... (version......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

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

Name of Participant

Name of Person

taking consent

Date

Date

·····

When completed, 1 for participant; 1 for researcher site file





Signature

Signature

# APPENDIX 5: COREC approval letter and substantial amendment letter



National Research Ethics Service

Barnet, Enfield & Haringey Local Research Ethics Committee

R&D Dept, **Royal National Orthopaedic Hospital Brockley Hill** Stanmore HA7 4LP

> Telephone: 020 8909 5318 Facsimile: 020 8385 7151

09 July 2007

Miss Joanna C Barlas **Trainee Clinical Psychologist** University College London Sub-Department of Clinical Health Psychology University College London Gower Street, London WC1E 6BT

**Dear Miss Barlas** 

#### Family members' experiences of mental illness and Full title of study: violence: Version 1 7

**REC reference number:** 

Thank you for your letter of 2<sup>nd</sup> July, 2007 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the Sub-Committee of the REC held on 05 July 2007. A list of the members is attached.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research as revised.

#### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

#### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

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

Document	Version	Date
Application	1	
Investigator CV		

This Research Ethics Committee is an advisory committee to London Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England



National Research Ethics Service

Barnet, Enfield & Haringey Local Research Ethics Committee

R&D Dept, Royal National Orthopaedic Hospital Brockley Hill Stanmore HA7 4LP

> Tel: 020 8909 5318 Fax: 020 8385 7151

30 November 2007

Miss Joanna C Barlas Trainee Clinical Psychologist Sub-Department of Clinical Health Psychology University College London Gower Street, London WC1E 6BT

**Dear Miss Barlas** 

Study title:	Family members' experiences of mental illness and violence: Version 1
REC reference:	
Amendment number:	1
Amendment date:	12 November 2007

The above amendment was reviewed by a sub-group of the Committee held on 27 November 2007.

#### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved were:

Document	Version	Date
Participant Information Sheet	2	
Summary of Changes to Protocol	1	
Notice of Substantial Amendment (non-CTIMPs)	1	

#### Membership of the Committee

The members of the Committee who reviewed the amendment are listed on the attached sheet.

#### **R&D** approval

**APPENDIX 6: Interview schedule** 

Barnet, Enfield and Haringey

Mental Health NHS Trust

### Family members' experiences of mental illness and violence

This study aims to investigate your experiences (as a family member or caregiver) of violence by a relative who suffers from mental health problems. It will look at what impact this violence has on yourself, your relationship with the individual and your beliefs about the responsiveness of services.

#### SEMI-STRUCTURED INTERVIEW SCHEDULE

#### **History of Relative's Mental Illness**

Could you give me a brief history of your relationship with X before X became mentally unwell?

When did you first notice X (the patient) becoming mentally unwell?

Do you know what X has been diagnosed with?

Could you describe how you felt when X was first diagnosed with a mental illness? (prompt: own emotions, thoughts and concerns about X)

How involved were you with X's care when X was diagnosed with a mental illness?

Could you describe what it was like living with/caring for X?

Did you have any fears or expectations about X becoming violent?

Did you witness or suffer any violence from X before X became mentally unwell?

#### **After Effects of Violence**

Has X ever been violent towards you or another family member since becoming unwell?

Could you describe a/the time when X was violent towards you/another family member/ a stranger?

How did you feel after the incident? (prompt: physically, emotionally, mentally)

What happened next in a practical sense? (police involvement, arrest etc)

What support were you offered? (immediately and long-term)

What effect did this violence have on you and your family?

- In the short-term?
- In the long-term?
- Personally?
- On your family relationships?

### **Coping and the Recovery Process**

What helped you to cope/recover?

Looking back is there anything that you think could have helped you to cope with the experience?

#### Impact of Violence on Relationship with Relative

What was your understanding of why X was violent?

Looking back is there anything that you think could have been done to prevent the violence?

To what extent are you (or your family) still involved with X now?

What is your (and their) relationship with X like now?

#### **Understanding of Service Provision**

What do you think about X's detention in a medium secure unit?

What do you think about the care X is receiving?

What, if anything, do you think about the future?

#### **Closing Questions**

Is there anything else you like to tell me about this experience?

How has it been talking to me about this experience?

# **APPENDIX 7: IPA Stage 1**

#### **IPA Stage 1: Extract from interview 7**

P7: We're believing that he's mentally unstable so if all the court are believing it, why ain't the doctors?! And it's... ohhhh! And he spent six months in prison where he shouldn't have been for all this process of law to go through and he was then sent to [name of private secure unit] and he spent, how much, six months up there after he come out of prison then he went down to [name of secure unit] where he was gonna go in the first place but they couldn't accommodate him at that time. And uh... I know it's a bad thing to say but I think it's a bloody good thing he attack this guy cos it's the only way he got bloody help. And he was a wreck, but you see him now and he's a normal person. Yeah, I don't know if you've met him? He's a normal guy, you can talk to him, you can laugh with him, you can joke with him and before I couldn't say anything to him. Cos on his 21<sup>st</sup> birthday and he went off and I got a phonecall, he says you can have your hundred pound back he says, I'm not gonna be bribed. This was over the phone and I, what? I don't know, something had snapped somewhere. This is what he was like. Oh he's a normal bloke now, if you met him in the street you wouldn't know there's anything wrong with him.

- Knowing he needs treatment but not being listened to
- Prison is the wrong place
- Frustration with the legal aspects of the system
- Positive aspects of violence in that it leads to getting help
- From a wreck to being normal
- Talking and laughing
- Couldn't say anything without setting him off
- Rejecting birthday present
- What's going on? Something's snapped
- Normal bloke now
- Nothing wrong with him

#### **IPA Stage 1: Extract from interview 10**

P10: I suffer more from guilt actually, yeah um... (crying)... I mean I feel that we must have been really poor parents, that's it in a nutshell, for this to have happened...(crying)... and that's why I think [son]'s angry with us as well because he looks around at his friends and sees their family life and ours, apparently, compares very unfavourably so. What I am continually asking for is some kind of support or therapy. I mean, you know, the whole family unit is, I feel, the reason that [son] is in this situation. And I think we should be treated as a unit and helped and supported. But there doesn't seem to be any, apart from this group, which is helpful, I find it helpful. I mean it's not really therapy. It's more to do with the business of it. I mean, as I said, if I'd been able to persuade [son] to go with me to talk to someone or go on his own to talk to someone if he preferred or for the family to talk to someone that's really what we wanted. I mean the [clinic] is all very fine but its really it seems more for people, for middle class people who have got a problem and not people like us with a severe problem. You know a real, deep psychiatric problem.

- Suffering from guilt
- Must have been poor parents
- Son's anger
- Wants support or therapy
- Family unit is the reason
- Wants family therapy but not available
- Carers' group helpful but not substitute for therapy
- Tried to get therapy for son before index offence
- Dissatisfaction with services offered
- Real, deep psychiatric problem

# **APPENDIX 8: IPA Stage 2**

#### **IPA Stage 2: Extract from interview 7**

P7: We're believing that he's mentally unstable so if all the court are believing it, why ain't the doctors?! And it's... ohhhh! And he spent six months in prison where he shouldn't have been for all this process of law to go through and he was then sent to [name of private secure unit] and he spent, how much, six months up there after he come out of prison then he went down to [name of secure unit] where he was gonna go in the first place but they couldn't accommodate him at that time. And uh... I know it's a bad thing to say but I think it's a bloody good thing he attack this guy cos it's the only way he got bloody help. And he was a wreck, but you see him now and he's a normal person. Yeah, I don't know if you've met him? He's a normal guy, you can talk to him, you can laugh with him, you can joke with him and before I couldn't say anything to him. Cos on his 21<sup>st</sup> birthday and he went off and I got a phonecall, he says you can have your hundred pound back he says, I'm not gonna be bribed. This was over the phone and I, what? I don't know, something had snapped somewhere. This is what he was like. Oh he's a normal bloke now, if you met him in the street you wouldn't know there's anything wrong with him.

#### IPA Stage 2: Extract from interview 10

P10: I suffer more from guilt actually, yeah um... (crying)... I mean I feel that we must have been really poor parents, that's it in a nutshell, for this to have happened...(crying)... and that's why I think [son]'s angry with us as well because he looks around at his friends and sees their family life and ours, apparently, compares very unfavourably so. What I am continually asking for is some kind of support or therapy. I mean, you know, the whole family unit is, I feel, the reason that [son] is in this situation. And I think we should be treated as a unit and helped and supported. But there doesn't seem to be any, apart from this group, which is helpful, I find it helpful. I mean it's not really therapy. It's more to do with the business of it. I mean, as I said, if I'd been able to persuade [son] to go with me to talk to someone or go on his own to talk to someone if he preferred or for the family to talk to someone that's really what we wanted. I mean the [clinic] is all very fine but its really it seems more for people, for middle class people who have got a problem and not people like us with a severe problem. You know a real, deep psychiatric problem.

- Recognition of mental health problems, but not by services
- Rejection of criminality
- Relief at finally getting mental health treatment
- Well vs. unwell person
- Importance of sense of humour
- Hostile relationships
- Back to normal
- Guilt
- Blaming self for anger and violence
- Therapeutic needs
- Family responsibility for violence
- Therapeutic needs not being met by services
- Difficulty in accessing services without relative volunteering
- Recognition of mental health problems

# **APPENDIX 9: IPA stage 3**

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#### **IPA Stage 3: Extract from interview 7**

P7: We're believing that he's mentally unstable so if all the court are believing it, why ain't the doctors?! And it's... ohhhh! And he spent six months in prison where he shouldn't have been for all this process of law to go through and he was then sent to [name of private secure unit] and he spent, how much, six months up there after he come out of prison then he went down to [name of secure unit] where he was gonna go in the first place but they couldn't accommodate him at that time. And uh... I know it's a bad thing to say but I think it's a bloody good thing he attack this guy cos it's the only way he got bloody help. And he was a wreck, but you see him now and he's a normal person. Yeah, I don't know if you've met him? He's a normal guy, you can talk to him, you can laugh with him, you can joke with him and before I couldn't say anything to him. Cos on his 21<sup>st</sup> birthday and he went off and I got a phonecall, he says you can have your hundred pound back he says, I'm not gonna be bribed. This was over the phone and I, what? I don't know, something had snapped somewhere. This is what he was like. Oh he's a normal bloke now, if you met him in the street you wouldn't know there's anything wrong with him.

#### **IPA Stage 3: Extract from interview 10**

P10: I suffer more from guilt actually, yeah um... (crying)... I mean I feel that we must have been really poor parents, that's it in a nutshell, for this to have happened...(crying)... and that's why I think [son]'s angry with us as well because he looks around at his friends and sees their family life and ours, apparently, compares very unfavourably so. What I am continually asking for is some kind of support or therapy. I mean, you know, the whole family unit is, I feel, the reason that [son] is in this situation. And I think we should be treated as a unit and helped and supported. But there doesn't seem to be any, apart from this group, which is helpful, I find it helpful. I mean it's not really therapy. It's more to do with the business of it. I mean, as I said, if I'd been able to persuade [son] to go with me to talk to someone or go on his own to talk to someone if he preferred or for the family to talk to someone that's really what we wanted. I mean the [clinic] is all very fine but its really it seems more for people, for middle class people who have got a problem and not people like us with a severe problem. You know a real, deep psychiatric problem.

- Theme 2: Seeking outside help
- Theme 5: Illness not criminality
- Theme 6: From prison to MSU
- Theme 3: On edge all the time
- Theme 11: Future hopes and concerns
- Theme 7: Continued suffering
- Theme 8: Looking for understanding

• Theme 13: Looking back – what was needed