PSYCHOLOGICAL IMPACTS FOR FAMILY MEMBERS CARING FOR PEOPLE WITH MENTAL HEALTH AND ALCOHOL PROBLEMS

by

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A THESIS SUBMITTED TO THE UNIVERSITY OF BIRMINGHAM FOR THE DEGREE OF DOCTOR OF CLINICAL PSYCHOLOGY

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Thesis Overview

This thesis was submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology at the University of Birmingham. The thesis consists of two volumes. Volume 1 contains three chapters related to the research component of the degree. Volume 2 consists of five reports, each representing clinical work undertaken on placements as part of the clinical component of the degree. To protect confidentiality, all identifying information relating to participants/service users has been changed within the thesis.

Volume 1: Research Component

Volume 1 focuses on understanding the psychological impacts on family members whose relatives have alcohol, mental and offending problems. It contains three chapters: a systematic review, an empirical paper, and a public dissemination document. The systematic review critically reviews quantitative literature of the prevalence and nature of the psychological impacts on the social network of heavy alcohol drinker and interprets the results in terms of the clinical implications for this group of people. The empirical paper uses Interpretative Phenomenological Analysis (IPA) to explore the psychological impacts on family members of men with mental health and offending problems. The findings are interpreted in relation to previous research and Lazarus' (1991) transactional model of stress and coping. The public dissemination document provides a brief summary of the systematic review and empirical paper in jargon-free language for the wider audience.

Volume 2: Clinical Component

Volume 2 consists of four Clinical Practice Reports (CPRs) and an abstract of an oral presentation all of which were completed over clinical placements to provide evidence of practice development over the three years of the course. CPR 1 presents a Cognitive Behavioural and a Behavioural case formulation of a 38-year old woman who experienced low mood, anxiety with panic attacks, agoraphobia, chronic low back pain and chronic widespread pain. CPR 2 details a case study of a 22-year old woman who experienced anxiety with panic attacks and dissociation, agoraphobia, depressive and trauma symptoms, and chronic low back pain in the context of a work-related accident. Case formulation and treatment were based on a Cognitive Behavioural Therapy. CPR 3 details a service evaluation which assessed whether the National Institute for Health and Care Excellence (NICE) guidelines for joint psychological-pharmacological intervention for depression have been followed in an older adult service and explored barriers to referring service users to psychology. CPR 4 describes a single case experimental design evaluating the effectiveness of a behavioural intervention for daytime enuresis in a 7-year old girl. CPR 5 involves an oral presentation detailing a case study of a 54-year old man with schizoaffective disorder and interpersonal difficulties which were challenging for the team supporting him. An abstract of the presentation is included.

Dedication

To my late mother and my late grandmother for their unconditional love, unwavering support and for teaching me to always persevere.

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First of all, I would like to thank my family and my partner for their confidence and belief in me throughout the duration of the program and for their support and continuous encouragement despite the distance.

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VOLUME ONE: RESEARCH COMPONENT

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Table of Contents

Volume One: Research Component

List of Figures

Volume One: Research Component

List of Tables

Volume One: Research Component

Table of Contents

Volume Two: Clinical Component

List of Figures

Volume Two: Clinical Component

List of Tables

Volume Two: Clinical Component

CHAPTER ONE - LITERATURE REVIEW

WHAT IS THE PREVALENCE AND NATURE OF THE PSYCHOLOGICAL IMPACTS OF HEAVY DRINKING ON THE SOCIAL NETWORK OF HEAVY DRINKERS?

Supervised by: Prof Alex Copello

Abstract

Background: Three million deaths worldwide are attributable to the harmful use of alcohol every year. Excessive drinking significantly affects the physical and psychological well-being of problem drinkers and of people around them. Impacts on partners of heavy drinkers include intimate partner violence, marital problems, poor quality of life, and stress. Psychological impacts on partners have been documented as well, however, these were usually based on studies with pre-selected, small samples.

Objective: The present systematic review aimed to examine the prevalence and the nature of the psychological impacts on the social network of heavy drinkers. It examined papers of general population surveys with large, randomly selected samples.

Method: A systematic literature search of published quantitative studies in three databases was conducted. A total of nine relevant papers were identified and reviewed.

Findings: The general prevalence of harms experienced from others' drinking ranged between 28.8% and 34.9%. Problem alcohol use was associated with depression and anxiety in the social network of heavy drinkers and the severity of the impact increased with the closeness of the relationship. However, the impact may be mediated by the negative consequences caused by the heavy alcohol consumption

rather than the alcohol consumption per se.

Conclusion: The findings highlight the need for more research on the impacts of heavy drinkers on their social network while controlling for potential confounders, using clear operational definitions and focusing on wider psychological impacts.

Keywords: problem drinking, family members, social network, psychological impact, prevalence

Introduction

1. The global impact of alcohol use.

Alcohol dependence has been defined as “a cluster of physiological, behavioural, and cognitive phenomena in which [alcohol use takes on a] higher priority … than other behaviours that once had greater value” (WHO, 2019). It is the most prevalent substance use disorder worldwide, with 100.4 million estimated cases in 2016 (Degenhardt, 2018). The Global status report on alcohol and health (WHO, 2018) reported that 3 million deaths worldwide were attributable to the harmful use of alcohol every year, which equals to 5.3% of all deaths in 2016. The same report also stated that 5.1% of the global burden of disease and injury is attributable to alcohol, as measured in disability-adjusted life years.

In Europe, 618,000 deaths and 17 million life-years lost due to disability and death were attributed to alcohol use in 2004 and alcohol was the second largest risk factor for death and disability (Moller & Matic, 2010).

2. The impacts and harms on the problem drinker.

The physical and mental health impacts of harmful drinking on the problem drinker have been well documented. These include increased risk of chronic illnesses such as cirrhosis of the liver (Thun et al., 1997), cancer (Bagnardi, Blangiardo, La Vecchia, & Corrao, 2001), diabetes (Rehm et al., 2004; Wannamethee, Shaper, Perry, & Alberti, 2002), cardiovascular disease (Beilin, Puddey, & Burke, 1996; Reynolds et al., 2003; Mukamal et al., 2005), premature mortality (Tolstrup, Jensen, Tjønneland, Overvad, & Grønbæk, 2004), and increased risk of fatal injury with an increasing volume of alcohol consumption (Cherpitel, Tam, Midanik, Caetano, & Greenfield, 1995; Macdonald et al., 2005; Paljärvi, Mäkelä, & Poikolainen, 2005).

The potential psychological impacts on those drinking include a well-established relationship with depression and anxiety (Alati et al., 2005; Hilarski & Wodarki, 2001; Schuckit, 1996; Rehm et al., 2004), sleep disorders (Stein & Friedman, 2005), risk of suicide and suicide attempts (Lesage et al., 1994; Andrews & Lesinsohn, 1992; Rossow, 1996), alcohol dependence (Caetano & Cunradi, 2002; Wagner & Anthony, 2002), and cognitive impairment and dementia (Antilla et al., 2004; Oscar-Berman & Marinkovic, 2003; Williams & Skinner, 1990). However, it is well documented that impacts and harms are not solely related to the person who is consuming the alcohol but that they also affect the drinker's immediate social network and society at large.

3. The impacts on society.

The societal impacts due to the harmful use of alcohol have been well documented and, in some instances, quantified. These include traffic accidents caused by people driving under the influence (Miller & Blewden, 2001; Miller, Lestina & Spicer, 1998; Moscowitz & Fiorentino, 2000), crimes such as assaults, homicides, damage to property, noise, fear, and harassment (Huhtanen & Tigerstedt, 2012; Norström, 1998; Johansson et al., 2006), and the costs to children of problem drinkers in terms of health, psychological difficulties and care utilisation. Connor and Casswell (2009) reported that between 2003-2007, more than 40% of alcohol-related crash injuries in New Zealand affected people who had not themselves been drinking and that alcohol-related injuries to victims cost the country more than half a billion dollars per year. Furthermore, Connor, You and Casswell (2009) found that more than half of the reported assaults in New Zealand were carried out by perpetrators who have been drinking. This represented 62,000 physical and 10,000 sexual

assaults every year. Anderson and Baumberg (2006) reported that the estimated economic cost of alcohol-attributable crime was 33 billion euros in the European Union (EU) for 2003.

The impact on children of problem drinkers in terms of Foetal Alcohol Syndrome (FAS) has been estimated as 0.5 to 2.0 per 1 000 live births in the United States and the annual cost of treating children with FAS at $76.4 million (Abel & Sokol, 1991; May & Gossage, 2001). In addition, in analysing a nationally representative sample of parents and children, Balsa and French (2012), found a positive and significant association between parental high intensity drinking and paediatric visits for their children and they also found evidence linking parental drinking to more emergency room use. The emotional and behavioural problems in children of alcoholics have been documented as well (Christensen & Bilenberg, 2000; Loukas et al., 2001).

To the costs reported above, we could also add impacts such as loss of productivity in the workplace and absenteeism (Moller & Matic, 2010). Using self-reported measures of alcohol-related absenteeism in Australia, Pidd, Berry, Roche, and Harrison (2006) estimated that 2.6 million workdays were lost in 2001 due to alcohol use resulting in a cost of $437 million.

4. The impacts on family members.

Having established the significant negative impact of harmful drinking on society as a whole, it is important to consider the closest social system within which those with drinking problems exist and this is usually made up of the person's family. Family members are likely to have the closest and most frequent contact with the person and therefore the impact on them is likely to be even greater than the wider

impact on society in general.

Research has paid some attention to this area. The family members most studied have been the partners and the children of problem drinkers. Studies on children of problem drinkers have found that those growing up with a problem drinking parent have more substance abuse problems, increased mortality and increased hospitalisations due to violence (Christoffersen & Soothill, 2003) although resilience has also been reported suggesting impacts are not equally damaging to all (Velleman & Orford, 2013).

The impacts on the spouses of problem drinkers, on the other hand, have been studied in terms of the high prevalence of intimate partner violence (Aggarwal, Sinha, Kataria, & Kumar, 2016), increased marital difficulties (Marshal, 2003), the stresses and burden of caring for the problem drinker (Orford, Natera, Copello et al., 2005; Orford, Copello, Velleman, & Templeton, 2010) and the negative impact on their quality of life (Casswell, You, & Huckle, 2011; Birkeland et al., 2018). A number of studies of spouses of male problem drinkers have found a relationship between increased alcohol consumption in their male partner and increased mental health distress, specifically depression and anxiety in the female partner (Gohil, Patel, & Samani, 2016; Sedain, 2013; Kishor, Pandit, & Raguram, 2013; Gandhi, Suthar, Pal, & Rathod, 2017; Ariyasinghe, Abeysinghe, Siriwardhana, & Dassanayake, 2015). If, as the research discussed so far suggests, there is a high level of psychological impact and needs for family members of people with alcohol problems and these problems are highly prevalent in society, it becomes imperative to establish precisely the extent as well as the nature of these problems in order to plan an adequate response. Indeed, it has been suggested that the mental health impact of alcohol and

drug problems on families constitutes a major but neglected contributor to the global burden of adult ill-health (Orford et al., 2013).

5. Shortcomings of spousal psychological impact research to date.

Despite some exceptions, the majority of studies that have examined the psychological impact on family members of problem drinkers have used small samples, identified through clinical groups, i.e., drinkers seeking help or in treatment, and have thus, introduced bias in their findings (Gohil, Patel, & Samani, 2016; Jacob, Dunn, & Leonard, 1983; Kahler, McCrady, & Epstein, 2003; Sedain, 2013; Kishor, Pandit, & Raguram, 2013; Schuckit, Smith, Eng, & Kunovac, 2002; Gandhi, Suthar, Pal, & Rathod, 2017; Ariyasinghe, Abeysinghe, Siriwardhana, & Dassanayake, 2015). These studies are discussed in more detail in the discussion section and in the context of the results from the current systematic review. Whilst these studies can illustrate the extent of impacts on specific samples, it can say little about the extent of the problem in the general population. Therefore, two questions become key to this area, namely the prevalence of these problems in population samples and in addition the extent of psychological symptoms present in these groups. This is the specific focus of this review.

6. Rationale for the present review.

The present systematic review included studies that were selected for the quality of their methodological designs. They were the best quality articles available in order to address the questions above given that they are general population prevalence studies, based on large random samples, and the social network of the problem drinker in the studies self-identified as such.

When defining the topic for the current systematic review, a decision was

made to focus solely on alcohol rather than on substances as a whole, because alcohol is unique as being legal and socially acceptable in most countries. In contrast, people who use drugs are very likely to come into contact with the legal system and this adds another variable to the problematic use issue and its impact on the user's social network. Drug use and having a criminal record are also more stigmatised and this double stigma may further compound the problem (Hartwell, 2004; van Olphen, Eliason, Freudenberg & Barnes, 2009).

7. Aim.

The aim of the present systematic review is to examine the population prevalence and the nature of the psychological impact on the social network of problem drinkers. As such, it will examine papers of general population surveys with large, randomly selected samples.

In the literature, there is no commonly agreed definition of 'problem drinking'. Some researchers use alcohol dependence (Gohil et al., 2016; Jacob et al., 1983; Kahler et al., 2003; Sedain, 2013), others alcohol abuse (Rognmo et al., 2013; Schuckit et al., 2002; Tempier et al., 2006), and yet others problem (Berends, Ferris & Laslett, 2012; Casswell, You, & Huckle, 2010) or heavy drinking (Dawson et al., 2007; Dussaillant & Fernandez, 2015; Ferris et al., 2011; Homish et al., 2006). Some studies operationalise the definition in terms of frequency and quantity of drinking behaviours whilst others use quantitative questionnaires with cut off points to define problems e.g., CAGE, AUDIT. Equally, there is no agreed definition of 'negative impact'. The focus of this review, however, is on the impact of drinking on others.

For the purpose of the current systematic review hence the term 'problem drinking' has been used throughout to describe the phenomena under study,

however, it is important to acknowledge that this term encompasses a range of definitions used across different studies included and careful attention was paid to clarify discrepancies in use of terms across studies as part of the review process. For the present review, ‘problem drinking’ was defined as drinking that has caused a significant impact on the social network of the problem drinker as identified by the social network itself. Similarly, ‘negative impact’ was broadly defined as any negative psychological impact on the social network of the problem drinker as measured by various standardised and non-standardised tools.

Method

A preliminary search was carried out in PsycINFO to ensure that a comparable systematic review has not been carried out. To the author's knowledge and based on the review of the available literature, this is the first time that there has been a systematic review of the population prevalence and the nature of the psychological impact on the social network of problem drinkers.

1. Search Strategy

Three databases (PsycINFO, Embase and Medline) were systematically searched on 17 March 2019. Table 1.1 outlines the keywords used in the search strategy. In addition to relevant keywords, identified from the titles and keywords used in relevant papers, subject headings and adjacent search were used as well. The adjacent search terms were combined with the search terms for "alcohol problems" and are presented in Appendix One. The search was limited to peer-reviewed journals, English language and human population.

Table 1.1

Search Terms Used for the Systematic Search

Search term 1 AND	**Search term 2 AND**	**Search term 3**
alcohol intoxication/ or exp acute alcoholic intoxication/ or exp chronic alcoholic intoxication/ or exp alcohol abuse/ or exp alcoholism/ or exp binge drinking/ OR ("alcohol abus*" or "alcohol use*" or "alcohol dependen*" or "alcohol problem*" or alcoholism).tw. OR ("alcohol addict*" or "alcohol intoxicat*").tw.	family/ or exp cohabitation/ or exp marriage/ or exp family members/ or exp spouses/ or exp significant others/ or exp husbands/ or exp wives/ or exp couples/ OR caregivers/ or exp caregiver burden/ OR family relations/ or exp interpersonal relationships/ or exp marital relations/ OR (family or families or relative or relatives or partner* or couple* or husband* or wife or carer* or caregiver* or spouse* or "significant other").tw. OR (marriage or married).tw.	major depression/ or exp affective disorders/ or exp "depression (emotion)"/ or exp mental disorders/ OR anxiety/ or exp anxiety disorders/ or exp stress/ or exp chronic stress/ or exp psychological stress/ or exp stress reactions/ or exp adjustment disorders/ or exp caregiver burden/ or exp crises/ or exp distress/ or exp family crises/ OR mental health/ or exp emotional adjustment/ or exp well-being/ OR morbidity/ or disorders/ OR family crises/ or exp crises/ OR (stress* or depress* or anxiety or anxious or burden or mental* or negative or emotion* or wellbeing or conflict or "life satisfaction" or distress*).tw.

Note:
•'AND' and 'OR' are Boolean operators used to combine search terms
•adj2 is an adjacency operator used to search within two words
*Represents truncation

2. Inclusion and Exclusion Criteria

The results of the search were screened for eligibility against the defined inclusion and exclusion criteria listed in Table 1.2.

The inclusion criteria were: quantitative studies in English from peer-reviewed journals, psychological impact on the social network of the person with alcohol problem/abuse/dependence whose age was 18 years and above.

Reviews and editorials, articles not in English and published in not peer-reviewed journals were excluded. Problems other than alcohol use (gambling, gaming, social media addiction, tobacco, drugs) were excluded, as were articles examining the reasons for drinking rather than its impact on the social network. People in the social network of the problem drinker with co-morbid mental health or physical disorders were excluded because the impact of the problem drinking on them could not be attributed to the drinking per se. Problem drinkers below the age of 18 years were excluded as well.

Table 1.2

Inclusion and Exclusion Criteria for the Systematic Search

Inclusion Criteria	Exclusion Criteria
Quantitative studies	Reviews & editorials
Peer-reviewed journals	Persons affected by other substance abuse problems (gambling, gaming, social media addiction, tobacco, drugs)
English language	
Problem drinker is adult (18+ years)	
Person with alcohol problem/abuse/ dependence only	Articles examining causes of alcohol abuse rather than its impact on the social network
Social network of problem drinker	
Psychological impact on social network	Impact on psychological/mental health of social network not examined
	Persons in social network with other co-morbid mental and physical disorders

3. Study Selection

The search of the three electronic databases identified 7,482 references. Figure 1.1 presents the systematic process of study selection. After deduplication, the titles of 7,477 references were screened. After screening the titles, the abstracts of 80 articles were screened. After scanning the abstracts 26 studies focusing on the psychological impact on the social network of problem drinkers were identified. The reference section of each of these articles was inspected to identify further studies. Thus, 36 studies were checked against the inclusion and exclusion criteria. Two articles focused on the impact on children, two were conference papers, 11 did not include a measure of psychological impact, two did not look at alcohol consumption per se and 10 used pre-selected samples, (e.g., the partners of men who were already in treatment or seeking help for alcohol abuse). In total, nine references were deemed appropriate for inclusion in the present review.

A summary of the studies included in the systematic review is presented in Table 1.3.

The frameworks from Tooth et al. (2005), Hoy et al. (2012), and von Elm et al. (2007) on observational studies were used to assess the articles. The quality rating of the articles is presented in Table 1.4.

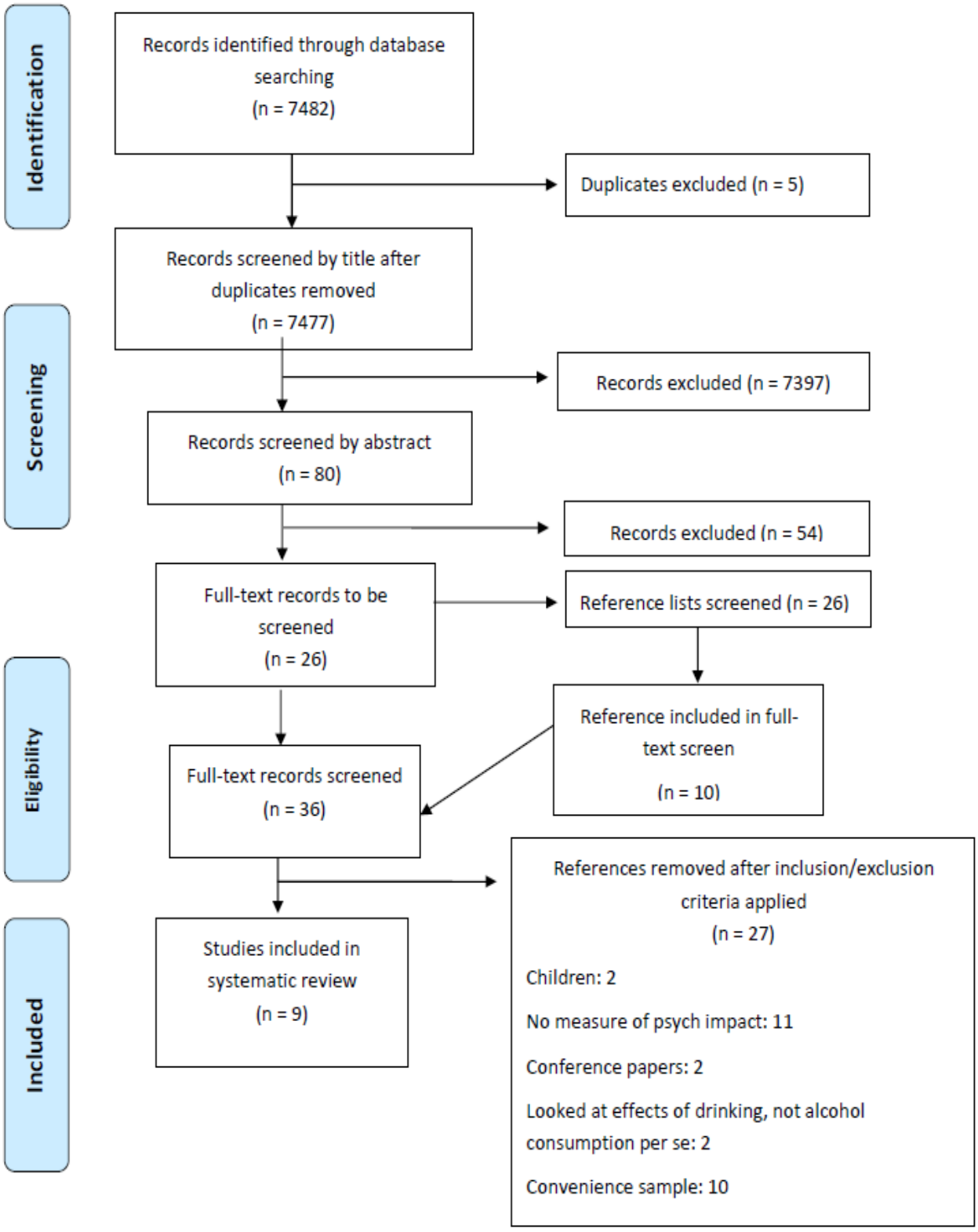

Figure 1.1 Flow chart of search strategy.

Table 1.3

Summary of systematic review studies (n = 9)

STUDY & COUNTRY	TYPE OF STUDY	AIM	PARTICIPANTS	METHODOLOGY	RESPONSE RATE	RELEVANT FINDINGS	PSYCHOLOGICAL IMPACT DUE TO HEAVY ALCOHOL CONSUMPTION
Berends, Ferris & Laslett (2012) Country: **Australia**	Cross-sectional study based on a national survey (alcohol-related harms experienced by others) administered by telephone.	Assess frequency and severity of negative impact on the general population, of family member who is problematic drinker; familial relationship and sex of problematic drinker.	N = 2649 adults in the survey [who reported knowing 8918 drinkers] **Age**: 18+ years Of the above sample, the authors selected: n (study) = 415 respondents affected by 592 heavy drinkers	**Sampling**: Random **Measures**: Questions about heavy drinking family member and negative impact on respondent. **Time frame**: previous 12 months **Analysis**: Bivariate & multivariate analyses	The survey had a cooperation rate[1] of 49.7% & a response rate[2] of 35.2%.	*Most respondents affected by problematic drinkers were female (77.6%). *Problematic drinkers in the family were typically male (72%). *The majority of problematic drinkers in the home were the respondent's partner (45.9%) or child (23.5%). *The proportion of respondents reporting severe harm is greater for those who live with the problematic drinker than those who do not. *One-third of respondents were negatively affected a lot by the heavy drinker. Half of these lived with the problematic drinker (partner 22%, child 20.3%, sibling 18.4%).	Yes

[1] The cooperation rate is the proportion of contacted individuals who agreed to participate in the survey (Lavrakas, 2008).
[2] The response rate is the number of people who completed the survey divided by the total sample (Saldivar, 2012).

						*Respondents who were negatively impacted by a male relative not living in the home, were so by an ex-partner.	
Casswell, You, & Huckle (2010) Country: **New Zealand**	Cross-sectional general population survey administered by telephone.	Investigate relationship between exposure to heavy drinkers and health status and well-being.	N = 3068 general population participants **Age**: 12-80 years	**Sampling**: Random **Measures**: EQL-5, PWI, self-reports of drinking; index of exposure to heavy drinkers **Time frame**: past 12 months (except EQ5-D health state today) **Analysis**: Regression and proportional odds models	Response rate 64%	*More than 1 in 4 respondents had a heavy drinker in their environment and this was associated with lower health status and personal well-being. *The greater the exposure to heavy drinkers the lower the health status and well-being of the respondent. *People exposed to heavy drinkers experienced significantly more anxiety & depression and this increased with the level of exposure defined as the amount of time the heavy drinker lived in the household. *75.2% of respondents with a heavy drinking partner were in the highest exposure group.	Yes
Dawson, Grant, Chou, & Stinson (2007) Country: **USA**	Cross-sectional, retrospective national comorbidity survey collected through personal interviews.	Examine association between current male-partner alcohol problems and	N (survey) = 43093 n = 232 married or cohabiting women with partners with current alcohol problems	**Sampling**: random **Measures**: DSM-IV criteria for mood and anxiety disorders; AUDADIS-IV; SF-12 v2; Nb. of past year	Survey response rate was 81% (N=43093).	*Women with partners with alcohol problems had higher rates of mood and anxiety disorders (3 & 2 times, respectively) and lower level of psychological quality of life compared to women with partners without alcohol problems and this remained true even when women's own	Yes

		physical and mental health outcomes in their female partners.	n = 11451 married or cohabiting women with partners without current alcohol problems **Age**: 18+yrs Age M=42.4 yrs., 71.5% White, 85.5% married, 55.4% had children <18yrs	stressors; victimisation; self-perceived health status **Time frame**: past 12 months **Analysis**: Bivariate & multivariate logistic & linear regression models.		alcohol use problems were controlled for.	
Dussaillant & Fernandez (2015) Country: **Chile**	Cross-sectional; face-to-face national survey.	Assess degree to which relationships with heavy drinkers affect health and well-being of Chilean population and compare this to Australian study.	N = 1500 general population n = 1130 (used in analyses) **Age**: 18+ years Socio-demographic variables were described & controlled for.	**Sampling**: random **Measures**: PWI, EQ-5D, WHO questionnaire **Time frame**: not reported **Analysis**: Bivariate analyses & multivariate regression models	Survey response rate 71.8%.	*Heavy drinkers inside the household negatively affect the health and well-being of Chileans. *This is true also for heavy drinkers outside the household but to a lesser degree.	Yes
Ferris, Laslett, Livingston, Room, &	Cross-sectional, national survey	Analyse links between other	N = 2622 general population	**Sampling**: random **Measures**:	Not reported.	*Identification of at least one heavy drinker in the respondent's social network was significantly associated	Yes

Wilkinson (2011) Country: **Australia**	administered by telephone.	people's drinking and mental health and explore effect on mental health of heavy drinkers.		Mental well-being item; EQ-5D, SF-12 **Time frame**: Not specified **Analysis**: secondary analysis of general population survey. Bivariate analyses & multivariate regression models.		with poor self-reported mental wellbeing and anxiety or depression. *When the respondent's life was adversely affected by a heavy drinker in the past year, the adverse effect on her mental well-being and anxiety was much greater.	
Homish, Leonard, & Kearns-Bodkin (2006) Country: **USA**	3 year-longitudinal study of marriage and alcohol involvement	Understand the relation between alcohol use and alcohol-related problems in one spouse and his/her partner's depressive symptomatology.	N = 978 community sample of newly married couples n = 634 couples analysed 590 couples completed questionnaires in 1 and 2 years Age: Men M=28.7 [18-69] years, Women M=26.8 [18-50] years; Majority: European	**Measures**: CES-D; Nb. of drinks & frequency of drinking **Time frame**: past 12 months **Analysis**: Multilevel modelling	Couples' participation across the 3 years was high, 74.5%.	*Marital problems brought on by alcohol use in men, but not alcohol consumption per se were related to wives' level of depression. *Wives heavy drinking, marital alcohol problems, and other alcohol problems were significantly associated with their own depressive symptoms. *Wives alcohol consumption was not associated with husbands' depressive symptoms.	No

			American, fairly well educated, employed, 38% men & 43% women were parents; 70% of couples had cohabited an average 21 months before marriage				
Nayak, Patel, Bond, & Greenfield (2010) Country: **North Goa, India**	Large population study on alcohol use patterns and sexual risk behaviours.	Role of partner alcohol use in women's depressi on.	N = 821 women [Cases 651, controls 170] **Age**: 18-49 years Socio-demographic variables were described & controlled for.	**Sampling**: purposive to represent Northern Goa's rural and urban population **Measures**: GHQ; US National Alcohol Surveys items, AUDIT, violence questions **Time frame**: past 12 months **Analysis**: Logistic regression models	Refusal rates for the interviews were low (<1%).	*Excessive partner alcohol use increased the risk for common mental disorders 2 to 3-fold, above and beyond significant socio-demographic risk factors. *Partner violence and partner alcohol-related problems mediated the association of partner excessive alcohol use with women's common mental health disorders.	Yes
Rognmo, Torvik, Roysamb, & Tambs (2013)	Cross-sectional study, based on a health screening survey in a	Investiga ted the relation between high alcohol	N (survey) = 77659 N (study) = 11584 couples	**Measures**: numerical indicators of alcohol amount, frequency of drinking, CAGE	59.5% response rate for individuals returning both Q1 and	*Alcohol consumption per se was significantly associated with a decrease in spousal mental distress. *Alcohol-related problems	No

Country: **Norway**	region in Norway.	consumption & alcohol problems in men and women, and their spouses' mental distress.	Men age M=48.5 years, Women M=45.7 years **Age**: 20-70 years	Alcohol Screening Questionnaire; HADS, CMD **Time frame**: 1-month period for drinking (current); lifetime for alcohol-related problems; 1 week prior to questionnaire for the HADS, 2 weeks for Connor Mental Distress index (CMD) [current] **Analysis**: Multivariate hierarchical regression analyses	Q2.	were associated with an increase in spousal mental distress.	
Tempier, Boyer, Lambert, Mosier, & Duncan (2006) Country: **Québec, Canada**	Cross-sectional study. Secondary analysis of general population health survey.	Examine the relationship between alcohol misuse in male partner & consequences on female spouse.	N = 11323 representative households; n = 864 couples were included in the study [Control group=4427] general, nonclinical population; men at lifetime at risk-drinking (min 2 positive	**Sampling**: random **Measures**: CAGE, IDPESQ 29 **Time frame**: lifetime at-risk drinkers **Analysis**: Stepwise multiple regression	Response rate in the survey was 81%.	*26% of women living with a male lifetime at-risk drinker suffered from psychological distress. *Levels of psychological distress were 5.7% higher in female spouses of male lifetime at-risk drinkers as compared to females living with male non- drinkers.	Yes

			answers on the CAGE) Socio-demographic variables were described & controlled for.				

Table 1.4

Quality rating of the systematic review articles (n = 9)

Quality Criteria:	Berends, Ferris & Laslett (2012)	Casswell, You, & Huckle (2010)	Dawson, Grant, Chou, & Stinson (2007)	Dussaillant & Fernandez (2015)	Ferris, Laslett, Livingston, Room, & Wilkinson (2011)	Hornish, Leonard, & Kearns-Bodkin (2006)	Nayak, Patel, Bond, & Greenfield (2010)	Rognmo, Torvik, Roysamb, & Tambs (2013)	Tempier, Boyer, Lambert, Mosier, & Duncan (2006)
INTRODUCTION									
Scientific background & rationale stated	++	++	++	++	+	++	++	++	++
Objectives/ hypotheses stated	++	++	++	++	++	++	++	++	++
METHODS									
Target population defined	++	++	++	++	++	++	++	++	++
Sampling frame defined	++	++	++	++	++	++	++	++	++
Study population defined	++	++	++	++	++	++	++	++	++

Study population representative of national population	++	++	++	++	++	+	-	++	++
Random selection used	++	++	++	++	++	-	++	++	++
Setting and/or geo-location stated	++	++	++	++	++	++	++	++	++
Period study was conducted is stated	++	++	++	++	++	-	-	++	+
Eligibility criteria stated	++	++	++	++	+	++	++	++	++
Aspects resulting in selective choice of participants mentioned	+	+	++	-	-	+	++	-	-
Number of participants justified	-	-	+	-	-	-	-	-	-
Numbers meeting and	-	++	++	++	-	++	++	-	-

not meeting the eligibility criteria stated									
Reasons for not eligible participants stated	++	-	++	++	-	++	++	++	++
Number of people who did/did not consent to participate stated	++	-	-	-	-	++	++	-	-
Reasons to decline participation stated	-	-	-	-	-	-	-	-	-
Consenters & non-consenters compared	-	-	-	-	-	++	-	-	-
Number of participants at start of study stated	++	++	++	++	++	++	++	++	++
Response rate reported	++	++	++	++	-	++	++	++	++

Attrition rate stated	N/A	N/A	N/A	N/A	N/A	+	-	N/A	N/A
STATISTICS AND RESULTS									
Methods of data collection stated	++	++	++	++	++	++	++	++	++
Reliability of measurement methods stated	-	+	+	+	-	-	+	++	++
Validity of measurement methods stated	-	+	+	+	-	-	+	++	++
Confounders mentioned	-	+	++	++	++	++	++	++	++
Number of participants at each stage specified	++	N/A	-	++	++	++	++	++	++
Reasons for loss of participants quantified	++	N/A	N/A	++	-	++	++	-	N/A
Missing data at each stage mentioned	++	N/A	N/A	++	++	++	++	++	-

Missing data accounted for in analyses	NR	N/A	N/A	++	NR	++	++	++	N/A
Loss of participants accounted for in analyses	NR	N/A	N/A	++	N/A	++	++	++	N/A
Confounders accounted for in analysis	-	++	++	++	++	++	++	++	++
Impact of biases assessed qualitatively	-	+	-	-	-	++	++	++	+
Impact of biases assessed quantitatively	+	-	-	-	-	-	++	+	-
DISCUSSION									
Limitations	++	+	++	++	+	++	++	++	++
Generalisability discussed	-	-	-	-	+	++	++	++	-

The frameworks from Tooth et al. (2005), Hoy et al. (2012), and von Elm et al. (2007) on observational studies were used to assess the articles.

Key: ++ The study was designed/conducted in a way that minimises the risk of bias.
+ The study did not address all potential sources of bias, or the answer is unclear from the way the study is reported.
− Significant sources of bias may persist.
(NR) Not reported. The study did not report how they have considered the aspect in question. (N/A) Not applicable. Study design aspects are not applicable to the given study design.

Overview of the Quality of the Selected Studies

In terms of quality, most studies were designed and conducted so as to limit the risk of biases. All studies, except Homish et al. (2006) used random sampling and in all studies, except in Nayak et al. (2010), the study sample was reported as representative of the national population. Similarly, all studies except Ferris et al. (2011) provided the response rate and all studies except Berends et al. (2012), reported possible confounders in their data analysis. Only Dawson et al. (2007) did not report the number of participants at each stage of their research.

Dawson et al. (2007) and Nayak et al. (2010) stated and described aspects of recruitment that may have resulted in a selection bias, however, only Dawson et al. (2007) justified the number of participants selected. Since most studies were large scale national surveys, the authors may have felt that any possible selective participation bias may have been mitigated by the large number of participants. Half of the studies did not describe (Berrends et al., 2012; Ferris et al., 2011; Rognnmo et al., 2013; Tempier et al., 2006) the number of participants meeting and not meeting the eligibility criteria. Only Casswell et al. (2010) and Ferris et al. (2011) did not state the reasons for the ineligibility of participants. Most studies also did not state how many people did and did not consent to participate, in fact only Berends et al. (2012), Homish et al. (2006), and Nayak et al. (2010) reported it. None of the studies provided reasons for the people who did not consent to participate and only Homish et al. (2006) compared consenters and non-consenters.

As most studies were surveys, the attrition rate was not relevant to them. Of the two longitudinal studies selected, Homish et al. (2006) reported an attrition rate

of 25.5% and Nayak et al. (2010) did not report the attrition rate.

Rognmo et al. (2013) and Tempier et al. (2006), reported the reliability and the validity of the measures they used. Berends et al. (2012), Ferris et al. (2011), and Homish et al. (2006) did not report specific measures or details of the questions asked and how these were arrived at. Casswell et al. (2010), Dawson et al. (2007), Dussaillant and Fernandez (2015), and Nayak et al. (2010) reported the measures used but gave no detail on their validity and reliability.

Homish et al. (2006), Nayak et al. (2010), and Rognmo et al. (2013) stated potential biases (such as selection bias) that may have affected the results but did not specify their magnitude. Only Nayak et al. (2010) had adjusted for design-related biases by using gender-specific weighs. Five studies did not discuss the generalisability of their results (Berends et al., 2012; Casswell et al., 2010; Dawson et al., 2007; Dussaillant & Fernandez, 2015).

In conclusion, the most problematic areas with the studies reviewed were (1) the fact that the number of eligible participants and non-consenters was not stated; (2) the consenters and non- consenters were not compared, and (3) the aspects that could have resulted in the selective choice of participants were not stated. The failure to compare consenters with non-consenters means that there remain concerns regarding whether the consenting participants had any systematic differences to those persons who withheld consent. However, this concern is somewhat mitigated by the large number of participants reported in the surveys.

The fact that biases were not stated and assessed may limit the confidence with which conclusions regarding the results could be drawn. Two (Homish et al., 2006; Rognmo et al., 2013) of the three studies that took biases into account did

not find a direct relationship between problematic drinking and psychological impact.

Overview of Identified Studies

1. Design

The studies selected were carried out on five different continents and in seven different countries including Australia, New Zealand, Chile, USA, Canada, Norway, and India. Only two (Homish et al., 2006; Nayak et al., 2010) of the nine studies selected are not general population surveys, however, the study by Homish et al. (2006) is a longitudinal study on marriage and alcohol involvement and the study by Nayak et al. (2010) is a large population study on alcohol use patterns and sexual risk behaviour in a large region in India.

2. Sample size and population

The total survey samples in the selected studies ranged from 821 to 77,659 participants. The sub-samples analysed in the nine studies ranged from 415 to 3,068 individuals or couples affected by a problem drinker for a total combined sample size of 22,515 participants.

Five of the studies looked at couples where the problem drinker was the male partner (Dawson et al., 2007; Homish et al., 2006; Nayak et al., 2010; Rognmo et al., 2013; Tempier et al., 2006), one study looked at family members (Berends et al., 2012), and three studies looked at the general population (Casswell et al., 2010; Dussaillant & Fernandez, 2015; Ferris et al., 2011).

3. Measures of psychological impact

Some national surveys used specifically developed questions to measure the psychological impact (Berends et al., 2012), whereas others used individual mental well-being items (Ferris et al., 2011). Most studies used a range of questionnaires ranging from general well-being questionnaires such as the European Quality of

Life – 5 Dimensions (EQ-5D) (Casswell et al., 2010; Dussaillant & Fernandez, 2015; Ferris et al., 2011), the Personal Wellbeing Index (PWI) (Casswell et al., 2010; Dussaillant & Fernandez, 2015), the Short Form-12 Health Survey Questionnaire (SF-12) (Dawson et al., 2007; Ferris et al., 2011), to more specific ones measuring depression such as the General Health Questionnaire (GHQ) (Nayak et al., 2010), the CONNOR Mental Distress Index (CMD) (Rognmo et al., 2013), the *Indices de détresse psychologique – Enquête Santé Québec* (IDPESQ 29) (Tempier et al., 2006), the DSM-IV criteria for mood and anxiety disorders (Dawson et al., 2007), the Hospital Anxiety and Depression Scale (HADS) (Rognmo et al., 2013), and the Center for Epidemiologic Studies Depression Scale (CES-D) (Homish, Leonard, & Kearns-Bodkin, 2006).

4. Measures of problem drinking

In order to assess problem drinking, the studies relied on the perception and interpretation of the respondents and used a range of measures with varying reliability and validity. Two studies (Berends et al., 2012; Ferris et al., 2011) did not report the questions they used to assess problem drinking. Three studies used specific questionnaires such as the Harm to Others from Drinking WHO questionnaire (Dussaillant & Fernandez, 2015) and the CAGE alcohol screening questionnaire (Tempier et al., 2006; Rognmo et al., 2013). The rest of the studies used a range of methods such as numerical indicators of alcohol amount and frequency of drinking (Homish et al., 2006; Nayak et al. 2010; Rognmo et al., 2013), an index of exposure to heavy drinkers (Casswell et al., 2010), and a specific definition (Dawson et al., 2007).

5. Time frames for the drinking and mental health measures

Most studies assessed problem drinking in the past 12 months. Two studies used different time frames, Rognmo et al. (2013) used one month for the problem drinking, and one to two weeks for the mental health measures, whereas Tempier et al. (2006) used lifetime at-risk drinking. Dussaint and Fernandez (2015) did not report the time frames that they used.

6. Findings

All studies found a negative impact on people close to a problem drinker, whether that was inside or outside of the household. However, two studies (Rognmo et al., 2013; Homish et al., 2006) found that the relationship between alcohol consumption and negative psychological impact in the person close to the problem drinker was not direct but was mediated by the negative consequences caused by the problem drinking.

Results

1. How prevalent is problem drinking of others as perceived by the respondents?

1.1. General population prevalence

Several studies in several different countries have looked at the general prevalence of heavy drinking as reported by the social network of the heavy drinker. In an Australian national survey on harms experienced from others' drinking (Berends et al., 2012) 2,649 randomly selected adults (18-98 years) reported 8,918 "drinkers". Of these 2,649 respondents, 28.8% (778) reported being affected by a problem alcohol drinker. Similarly, in New Zealand, Casswell et al. (2010) found that 29% of the 3,068 general population adults interviewed, reported having at least one heavy drinker in their social network. In Chile, Dussaillant and Fernandez (2015) analysed 1,130 valid cases of a national survey carried out with 1,500 adults. They found that 32.6% of respondents reported one or more heavy drinkers outside of the household, which is slightly higher than the prevalence reported by Berends et al. (2012) and Casswell et al. (2010) but similar to the prevalence reported by Ferris et al. (2011) in Australia. Ferris et al. (2011) found that 25.8% of respondents who reported feeling anxious or depressed knew one or more persons whom they would consider a heavy drinker and 34.9% of respondents who reported feeling anxious or depressed reported adverse effects from others' drinking.

Therefore, the prevalence of harms experienced from others' problem drinking appears to vary between 28.8% (Berends et al., 2012) and 34.9% (Ferris et al., 2011) in the general population. This is not a big variation and may be accounted for by differences in study design, cultural differences and different

operational definitions.

1.2. Household prevalence

Studies have also examined the household prevalence of heavy drinkers as reported by their family members and spouses.

1.2.1. Family members

Three studies (Berends et al., 2012; Casswell et al., 2010; Dussaillant & Fernandez, 2015) focused on family members. From 2,649 randomly selected adults, Berends et al. (2012) narrowed their focus down to 415 family members who reported experiencing a negative impact due to the drinking of a close relative. Of 8,918 drinkers, 1,494 (16.75%) were relatives and 592 (39.6%) of these, were the heavy drinkers that were reported to be negatively affecting 415 family members. The heavy drinkers in this study were typically male (72%) and the ones who lived in the household were the respondents' partner (45.9%) or child (23.5%). However, the high prevalence found by Berends et al. (2012) was not replicated by Casswell et al. (2010) who found that from the respondents who reported exposure to a heavy drinker, 26% of the heavy drinkers were living in the same household. An even lower prevalence was found by Dussaillant and Fernandez (2015) in Chile. The authors found that 16.2% of respondents reported one or more heavy drinkers in the household. This prevalence is less than that reported in New Zealand (26%) (Casswell et al., 2010) and Australia (39.6%) (Berends et al., 2012) and this could be due to cultural differences.

1.2.2. Heterosexual couples

Three studies (Dawson et al., 2007; Tempier et al., 2006; Nayak et al., 2010) focused on the prevalence in heterosexual couples. Nayak et al. (2010)

conducted a large population study on alcohol use patterns and sexual risk behaviours in Goa, India, where, of 2,658 households approached, 651 (30.89%) married non-alcohol drinking women reported having a heavy drinking partner. This prevalence was two times higher than the one found by Tempier et al. (2006) in a provincial general population survey in Canada. Of 11,323 households, the authors identified 5,535 heterosexual couples living together for at least 3 months and in 864 (15.61%) of these couples, the male partner was considered a lifetime at-risk drinker. However, Dawson et al. (2007) found the lowest prevalence in heterosexual couples. They used data from a national comorbidity survey where 43,093 adults were interviewed and focused on 11,683 women cohabiting with a male partner, among these the partners of 232 (1.99%) women had current alcohol problems.

Two papers (Homish et al., 2006; Rognmo et al., 2013) did not report the general population or household prevalence of heavy drinking.

Given that some studies did not report the prevalence of heavy drinkers in the social network of respondents and that some studies focused on heterosexual couples without reporting the prevalence in the general population sample from which the couples' sample was drawn, it is difficult to draw a definite conclusion about the prevalence of problem drinkers in the social network of respondents. However, provisionally, it seems that in the general population the prevalence of problem drinkers varies between 28.8% (Berends et al., 2012) and 34.9% (Ferris et al., 2011); in the household, the prevalence varies between 16.2% (Dussaillant & Fernandez, 2015) and 39.6% (Berends et al., 2012); and among couples, the prevalence varies between 1.99% (Dawson et al., 2007) and 30.89% (Nayak et al.,

2010). This variability in prevalence could be due to differences in study design, samples, cultures, definitions of problem drinking and differing timeframes (current versus lifetime).

2. Who are the respondents?

2.1. Female partners of heavy drinkers

Since most of the studies looked at heterosexual couples where the problem drinker was the male partner, the most frequently studied respondent was the female partner who experienced impacts from their spouse's drinking (Berends et al., 2012; Dawson et al., 2007; Nayak et al., 2010; Tempier et al., 2006; Rognmo et al., 2013; Homish et al., 2006).

2.2. Social network of heavy drinkers

Most other studies looked at the family members (Berends et al., 2012) and the wider social network of problem drinkers (Dussaillant & Fernandez, 2015; Ferris et al., 2011; Casswell et al., 2010). Berends et al. (2012) found that the problem drinkers in the home were the respondents' partner (45.9%) or child (23.5%) and that respondents who were negatively impacted by a male relative not living in the home, were so by an ex-partner. In contrast, Casswell et al. (2010) found that the most common relationship between the problem drinker and the respondent was friend (46%), wider family (21%), sibling (15%), partner (12%), and children (10%). Most studies have focused on the impact of men with a drinking problem on the female partner, however, studies also suggest that the wider social network of the heavy drinkers (such as ex-partners, friends, siblings, and parents) is impacted as well.

3. What is the impact reported by the respondents?

3.1. Negative impact

Most studies reported a negative impact on the social network of the problem drinker. Dussaillant and Fernandez (2015) found that heavy drinkers inside the household negatively affected the health and well-being of Chileans. This was also true of problem drinkers outside the household but to a lesser degree. This is similar to the findings of Berends et al. (2012) who found that the proportion of respondents reporting severe harm is greater for those who live with the problem drinker than for those who do not. In a study of heterosexual couples, Tempier et al. (2006) found that 26% of women living with a male lifetime at-risk drinker suffered from psychological distress and that the levels of psychological distress were 5.7% higher in female spouses of male lifetime at-risk drinkers compared to females living with male non- drinkers.

Problem drinkers negatively impact both people in their household and outside, however people in the household tend to be more affected very likely due to the closeness of the relationship.

3.2. Anxiety and depression

Studies also looked at specific impacts such as anxiety and depression on the social network of the problem drinker. Casswell et al. (2010) found that people exposed to heavy drinkers experienced significantly more anxiety and depression and this increased with the level of exposure. Specifically, 75.2% of respondents with a heavy drinking partner were in the highest exposure group. The greater the exposure to heavy drinkers the lower the health status and well-being of the respondent. Similarly, Dawson et al. (2007) found that women with partners with

alcohol problems had higher rates of mood and anxiety disorders, three and two times respectively, and lower level of psychological quality of life compared to women with partners without alcohol problems and this remained true even when the women's own alcohol use problems were controlled for. Ferris et al. (2011) also found that the identification of at least one heavy drinker in the respondent's social network was significantly negatively associated with self-reported mental wellbeing and anxiety or depression. In addition, the authors found that if the heavy drinker was someone whose drinking had had a negative impact on the respondent's life in the past year, the adverse effect on mental well-being and anxiety was much greater.

Studies show a negative impact and specifically anxiety and depression on the social network of the problem drinker and this impact grows stronger with the degree of exposure to the problem drinker.

3.3. Impact through different mechanisms

In contrast to the studies discussed above, three studies (Homish et al., 2006; Nayak et al., 2010; Rognmo et al., 2013) did not find that problem drinking had a negative impact on the social network of the drinker. Homish et al. (2006) found that marital problems brought on by alcohol use in men, but not alcohol use per se, were related to wives' level of depression. Similarly, Nayak et al. (2010) found that excessive partner alcohol use increased the risk for common mental disorders two to three-fold, above and beyond significant socio-demographic risk factors in their female partners. However, partner violence and partner alcohol-related problems mediated the association of partner excessive alcohol use with women's mental health disorders. In contrast, Rognmo et al. (2013) found that alcohol consumption was significantly associated with a decrease in spousal

mental distress, however, alcohol-related problems were associated with an increase in spousal mental distress.

It appears that problem alcohol use negatively impacts the social network of the heavy drinker, leading to depression and anxiety and that the severity of the impact increases with the closeness of the relationship with family members being affected more than the wider social network. However, it also seems that the impact may be mediated by other problems caused by the problem drinking rather than by the problem drinking per se.

Discussion

1. Summary of the results

The aim of the present systematic review was to examine the population prevalence and the nature of the psychological impact on the social network of problem drinkers. As such, it examined studies of general population surveys with large, randomly selected samples, where the self- identified respondent reported on the impacts of a problem drinker in their social network.

Although the data is limited, it appears that the general prevalence of harms experienced from others' drinking in the studies reviewed in the current systematic review, ranges between 28.8% (Berends et al., 2012) and 34.9% (Ferris et al., 2011). Inside the household, the prevalence varies between 16.2% (Dussaillant & Fernandez, 2015) and 39.6% (Berends et al., 2012) and among couples, the prevalence varies between 1.99% (Dawson et al., 2007) and 30.88% (Nayak et al., 2010). These differences could be due to different study designs, operational definitions, time frames (current v lifetime problem drinking and current v long-term negative impact), sampling, and cultural issues.

Most studies have focused on the impact on the female partner of men with a drinking problem, therefore most respondents were women cohabiting with a male partner. However, general population surveys also suggest that the wider social network of problem drinkers (ex-partners, friends, siblings and parents) is impacted as well.

The problem alcohol use appears to negatively impact the social network of the problem drinker, leading to depression and anxiety. In addition, the severity of the impact increases with the closeness of the relationship, with family members

being affected more than the wider social network. Some studies (Homish et al., 2006; Nayak et al., 2010) also suggest that the impact may not be direct but rather may be mediated by the negative consequences caused by the heavy alcohol consumption such as marital discord and partner violence.

The above findings are consistent with findings of studies with small, pre-selected samples of female spouses and carers of male problem drinkers. Kishor et al. (2013) studied 60 spouses of men with alcohol dependence syndrome in treatment at a hospital and found that 65% had a diagnosable psychiatric disorder. Ariyasinghe et al. (2015) interviewed 156 female spouses of men who used alcohol in two rural villages in Sri Lanka and found that one in three women had a major depressive disorder (MDD). Similarly, Sedain (2013) found high rates of depressive, conversion and anxiety disorders among 46 spouses of male alcoholic patients. Gandhi et al. (2017) compared 150 female spouses of men with alcohol use disorder with 150 controls and found significantly higher rates of depression and anxiety in the former. Similarly, Gohil et al. (2016) studied 110 carers of patients with alcohol dependence and found that 26% had dysthymia, 22% had major depression, 8% unspecified anxiety disorder, and 4.5% had generalised anxiety disorder.

Unlike the previous five studies, and similar to some of the large sample studies, three studies did not find an association between partner's heavy drinking and spousal distress. Schuckit et al. (2002) compared 235 controls and 92 women with husbands with alcohol abuse disorder (AAD) and found that the latter had a higher likelihood of substance abuse but did not have a higher risk for other major psychiatric disorders. The husbands of both groups were either university students

or non-academic staff, therefore, this well-educated and high functioning sample may be an important confounder. Similarly, Jacob et al. (1983) studied 27 spouses of male alcoholics from an ongoing family interaction study and found that high alcohol consumption was associated with high marital satisfaction and fewer psychiatric symptoms in the spouses. The authors hypothesised that women have adapted to their husband's drinking and this accounted for their high marital satisfaction. Another interesting finding was that by Kahler, McCrady, and Epstein (2003). These researchers studied 90 female non-alcoholic partners of alcoholic men seeking outpatient, conjoint alcohol treatment and found that greater psychological distress was strongly associated with lower frequency of partner's drinking and that severity of partner's alcohol problems was associated with greater marital satisfaction in multiple regression analyses but not in bivariate analyses. For both surprising findings, the authors urged caution and the need to be replicated with other samples as these results have not been previously reported in the literature. Concerning the first finding and based on previous research by Jacob, Dunn, and Leonard (1993), the authors hypothesised that spouses may deal better with a steady and predictable pattern of drinking rather than with a more episodic and erratic pattern. Concerning the second finding, the authors hypothesised that the men with more severe alcohol problems might have come more willingly to treatment and/or their wives were relieved that their partner was seeking help and thus were more hopeful about the relationship.

Based on the findings of the current systematic review, we could conclude that problem drinking is quite prevalent both in the general population and in the household and that the social network of the problem drinker is significantly and

negatively impacted, although the mechanism by which it is impacted requires more research.

2. Limitations of the studies reviewed

Given the current state of the research literature, it is difficult to draw general and definite conclusions due to the variability of the studies available for review in terms of their design, methodology, definitions and the measurement tools used. The studies also have limitations such as being self-reports and lacking clear, operational definitions of both ‘problem drinking’ and ‘negative impact’. This leaves the reported findings open to interpretation and makes comparisons between studies difficult and challenging as we cannot be sure that the authors refer to the same problem. Only three of the studies (Homish et al., 2006; Nayak et al., 2010; Rognmo et al., 2013) in the present literature review, operationalised heavy drinking in terms of frequency and quantity. The other studies used various questionnaires such as the WHO questionnaire (Dussaillant & Fernandez, 2015), the CAGE alcohol screening questionnaire, an index of exposure to heavy drinking, or a specific definition and some studies did not provide the definition that they used (Berends et al., 2012; Casswell et al., 2010; Dussaillant & Fernandez, 2015). In addition, some studies referred to ‘drinking’ whereas others referred to ‘heavy drinking’. Since there is no clear definition of the terms, we cannot be sure if the studies referred to the same problem. Similarly, most studies lacked a clear definition of ‘negative impact’ making comparisons between studies difficult. Some studies did not report the questions that respondents were asked (Ferris et al., 2011), some used specific questions developed for the survey (Berends et al., 2012), and others used a variety of questionnaires, ranging from more general

such as the EQ-5D (Casswell et al., 2010; Dussaillant & Fernandez, 2015; Ferris et al., 2011), the PWI (Casswell et al., 2010; Dussaillant & Fernandez, 2015), the SF-12 (Dawson et al., 2007; Ferris et al., 2011), to more specific ones measuring depression such as the GHQ (Nayak et al., 2010), CMD (Rognmo et al., 2013), the IDPESQ 29 (Tempier et al., 2006), the DSM-IV criteria for mood and anxiety disorders (Dawson, Grant, Chou, & Stinson, 2007), the HADS (Rognmo et al., 2013), and the CES-D (Homish et al., 2006). Even studies where negative impact was defined as anxiety and/or depression, did not specify the cut-off for the questionnaires used, making comparisons between studies that used the same questionnaires difficult.

The studies reviewed in the present paper also used different time frames. Whereas most studies focused on the past 12 months or current drinking, Tempier et al. (2006) focused on lifetime at-risk drinkers. These varying time frames may hide differences between long-term drinkers and recent drinkers as well as between episodic and regular drinkers, and this may affect the type of impact and the severity of the impact on the social network of the problem drinker.

The studies reviewed, also sampled different populations such as the wider social network, family members, and couples. This degree of closeness affects the impact of the problem drinking with partners and family members usually being affected more than friends and colleagues very likely because they are more exposed to the problem drinker. The majority of the studies that focused on partners looked at heterosexual couples but failed to take the length of the marital relationship into account and this could be a possible confounder. We could hypothesise that the longer the marital relationship, the stronger the impact on the

spouse would be or alternatively, we could hypothesise that if the relationship endured, the spouse may have adapted and accepted her partner's drinking, therefore, she may not be experiencing a negative psychological impact because she has learnt to cope with the problem drinking of her partner. Dawson et al.'s (2007) study tends to support the former view. They did not report the average length of the marital relationships of the couples in their study but considering that the mean age of the female partners in their study was 45.9 years and that 46.9% had children younger than the age of 18 years living at home, we could hypothesise that the majority of couples were not newly married. The authors found that the female spouses of problem drinkers had higher rates of mood and anxiety disorders compared to the spouses of men without alcohol problems. On the other hand, the stresses of a new marital relationship may have a stronger negative impact than high alcohol consumption per se because the couples may still be adjusting to life together. Homish et al. (2006) examined newly married couples and did not find a direct impact from heavy drinking, however, they found that marital problems brought on by alcohol use were related to the female partner's depression. Research has suggested that family members can experience negative impacts due to the harms and the compensatory actions they need to take as a result of someone's heavy drinking (Berends et al., 2012). Therefore, the results of Homish et al. (2006) could be understood in the context of female spouses needing to take on more of the responsibility in the marriage such as child care, household work or earning an income and this burden may lead to depression and marital dissatisfaction. In addition, marital relationships with problem drinkers are usually characterised by high levels of conflict and this may contribute to the female

partner's psychological distress (Kahler et al., 2003). More research is needed to elucidate the interaction between the length of the marital relationship and problem drinking also taking into account factors such as the presence and age of children in the household, marital conflicts, impairment in family functioning due to alcohol use, coping style of the spouse, personal disposition, sources of support, presence of other stressors, stress, violence, and degree of hardship.

In addition, in research on couples, the respondent's own mental health difficulties were not assessed prior to them living with a problem drinker. Psychological distress in the respondents may have occurred before them living with the alcohol abusing partner as these women may have come from disadvantaged backgrounds or for a variety of other reasons. In addition, studies have not usually assessed the spouse's own alcohol consumption, so the spouse's mental distress may be associated with her own alcohol abuse rather than with her partner's drinking. Homish et al. (2006) found some support for this hypothesis. They found that wives' heavy drinking was significantly associated with their own depressive symptoms but that their spouses' heavy drinking was not related to their level of depression. This finding could be understood in the context of concordant drinking, which was found to increase marital satisfaction (Homish & Leonard, 2007). However, Dawson et al., (2007) found that women with partners with current alcohol problems were five times more likely to have a past year alcohol use disorder than women without partners with alcohol problems but no evidence of increased marital satisfaction. Therefore, more research is needed to clarify under what conditions concordant drinking could lead to increased marital satisfaction.

Educational level of both the spouse and her problem drinking partner is

another factor that needs to be taken into consideration. Schuckit et al.'s (2002) sample consisted of the wives of university students or non-academic staff with alcohol abuse disorder and the majority of the wives themselves, 78.3%, had white-collar jobs. The authors did not find a higher risk for major psychiatric disorders, except for substance abuse among these women. In contrast, the sample in the Dawson et al.'s (2007) study was not educated to a high level, only 14.5% of women with a partner with an alcohol problem had completed college or higher education. The authors did not provide information on the problem drinker's educational level. Dawson et al. found that these women had higher rates of mood and anxiety disorders compared to women with partners with no alcohol problems. It is possible that more educated problem drinkers are 'higher functioning' or tend to be chronic rather than episodic drinkers and therefore this predictability may cause less distress to their partners. It is also possible that more educated female partners are 'higher functioning' themselves and more able to cope with and to find solutions to marital problems. Since the majority of the studies reviewed have not described or taken into account the problem drinker's and their partner's educational level more research is needed to establish its relationship to problem drinking and its impact on the social network of the problem drinker.

Another limitation of the studies reviewed here is that we cannot infer causation. There are three criteria for causation – association, chronology and control for third variables. Most of the studies have shown an association between problem drinking and negative psychological impact on the drinker's social network, however, chronology, i.e., that the problem drinking precedes the negative psychological impact is more difficult to be demonstrated in real-life, and not so

easy to accommodate in an experimentally controlled design. Similarly, a high number of the studies have not taken into consideration potential confounding variables. Therefore, in order to be better able to compare the diverse studies and to clarify the nature of the relationship between problem alcohol consumption and negative impact on the social network of the problem drinker, potential confounders such as sociodemographic variables (ethnicity, age, education, employment, income, children), marital problems, length of the marital relationship, degree of exposure to problem drinker, other stressful life events, personal disposition, coping styles of the partner, degree of hardship, and the respondents own drinking and pathology should be systematically considered and controlled for. The two studies (Homish et al., 2006; Rognmo et al., 2013) that took some of these potential confounders into account, did not find a direct relationship between high alcohol consumption and negative impact on the person close to the problem drinker, but rather found a negative impact as a result of the problems caused by the heavy drinking. Thus, the relationship between mental distress in the respondents and heavy alcohol consumption in the problem drinker may not be causally linked to consumption levels but could be mediated by other factors.

3. Strengths of the studies reviewed

A limitation but also a strength of the present systematic review is the fact that the studies used a variety of tools to assess problem drinking and negative impact and that despite this, the majority of the studies found an association between problem drinking and negative impact in the respondents.

Another strength of the current review is that the national surveys were carried out in diverse countries with varying cultures and traditions and the majority

of the studies (seven out of nine) found similar results to most of the small, pre-selected samples' studies (Gohil, Patel, & Samani, 2016; Kahler, McCrady, & Epstein, 2003; Sedain, 2013; Kishor, Pandit, & Raguram, 2013; Schuckit, Smith, Eng, & Kunovac, 2002; Gandhi, Suthar, Pal, & Rathod, 2017; Ariyasinghe, Abeysinghe, Siriwardhana, & Dassanayake, 2015) thus strengthening the conclusion that problem drinkers have a negative psychological impact on families and their social networks irrespective of cultural and other contextual differences.

4. Clinical implications

As previously pointed out, most studies demonstrate an association between problem drinking and negative impact on the drinker's social network however, studies lack clear operational definitions and have not taken important confounders into consideration. Therefore, caution should be used when designing policies as direct causal relationships between problem drinking and its negative psychological impact on the drinker's social network, cannot be inferred and the relationship is unlikely to be direct and simple. However, although the precise mechanisms of the relationship may not be clear, there is sufficient evidence that problem drinkers negatively affect people around them and policies that aim to address this negative impact will be beneficial.

From the available literature so far, we can conclude that the social network of problem drinkers seems to be a hidden group experiencing a significant psychological impact and deserving more attention. It also seems that family members may experience stigma about seeking help for the distress caused by their heavy drinking relative. In a world mental health survey across 16 sites in various countries and encompassing 81,144 family members, Ahmedani et al. (2013) found

that family members of relatives with alcohol, drug, or mental health conditions (ADMC) experienced more embarrassment than family members of people with General Medical Conditions (GMC) or with both ADMC and GMC and that this was not as a function of family burden.

Therefore, increasing awareness about the wider impact of problem drinking would, on one hand, make mental health professionals more aware about the significant psychological impacts on family members of problem drinkers and more aware of the need to find opportunities to assess them such as, for example, when problem drinkers consult. Second, more research on this topic would open more discussions about the impacts of heavy drinking and this, could decrease the stigma family members and others experience and this, in turn, could mobilise people affected by someone's problem drinking to seek help.

Governments could also raise awareness about this problem by organising campaigns to inform people. A systematic review of mass media messages to reduce alcohol consumption and related harms by Young et al. (2018) found that although there was no reduction in alcohol consumption, there were some increases in treatment seeking and information seeking. The authors concluded that the campaigns they reviewed, were associated with increases in knowledge about alcohol consumption. This shows that mass media or government campaigns could be a good way to increase people's awareness of this issue.

5. Future directions

In the future, in order to better clarify the relationship and the nature of the relationship between high alcohol consumption and negative psychological impacts on the drinker's social network, studies would benefit from using clear operational

definitions of ‘heavy drinking’ and ‘negative impact’. Researchers should also focus not only on the quantity of alcohol consumed but also on the level of impairment as alcohol affects people differently and some people remain high functioning despite the amount of alcohol they consume. Potential confounders should also be taken into consideration when designing studies as the relationship between problem drinking and negative impact in the social network of the problem drinker is likely multifactorial. In addition, broader psychological negative impacts such as biological (e.g., sleep and appetite disturbances), cognitive (e.g., memory difficulties), somatic disturbances (e.g., somatisation, hypertension, chronic pain) and behavioural (doctor’s visits) should be assessed.

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CHAPTER TWO - EMPIRICAL RESEARCH PAPER

A QUALITATIVE STUDY OF THE PSYCHOLOGICAL IMPACT ON FAMILY MEMBERS OF MEN ADMITTED TO MEDIUM SECURE FACILITIES DUE TO OFFENDING BEHAVIOUR AND MENTAL HEALTH DIFFICULTIES

Supervised by: Prof Alex Copello

Abstract

Introduction: Studies and recent government initiatives recognise the important role family members play in supporting relatives who have mental health difficulties and relatives who have offended. However, research on the impacts on main carers of people with both mental health and offending problems is lacking. Previous research on offending and on mental health, suggests that carers may experience stigma, isolation, psychological, relational and social burdens. Therefore, the aim of the current study was to examine these impacts on family members of men with mental health and offending problems.

Method: Semi-structured interviews were conducted with a purposively selected sample of six family members whose relative was detained in a medium-secure facility. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA).

Results: Four superordinate themes emerged and a drama plot metaphor was used to make sense of family members' experiences. The superordinate themes were prelude, which set the context to the problem; build-up which captured the journey through the system; culmination which captured the psychological impact of the build-up; and the resolution process which described the adaptation and acceptance process of family members.

Conclusions: The impact on family members of male relatives with mental health and offending problems is significant and needs to be addressed by government

policy and mental health services.

Keywords: Psychological impact, caregiver, family member, mental health, stress, coping, medium-secure setting, Interpretive Phenomenological Approach (IPA), qualitative research

Introduction

Good family relationships can increase employment, reduce homelessness, and reduce re-offending in offenders. Thirty-seven per cent of detained offenders who received at least one visit by family or partners, showed higher rates of employment, training, education (ETE) and housing on release compared to 16% of offenders not visited (Niven & Stewart, 2005). The frequency of visits also appeared to increase the likelihood of offenders having ETE arranged on release (40% of offenders visited at least once a month versus 27% receiving visits less often). Offenders who received visits were also less likely to re-offend within a year of release, 52% compared to 70% of offenders not visited (May, Sharma, & Stewart, 2008). Datchi, Barretti, and Thompson (2016) noted that families provide emotional, as well as practical support (housing, food, employment, and transportation) and by doing so reduce the likelihood of offenders re-establishing ties with criminal associates and re-engaging in criminal activity.

Policy and research increasingly recognise that strengthening family ties leads to better rehabilitation and psychological and behavioural outcomes including re-integration into society and lower recidivism rates. As Greenwood (2008) concluded in his review of community-based programs for young offenders, programs focused on the individual offender rather than the family were less successful. Evidence-based family-focused treatments have proven success with young offenders. A recent meta-analysis (Dopp, Bourduin, White, & Kuppens, 2017) summarised findings of 28 studies on family-based treatments for serious and violent juvenile offenders. The authors found modest (mean d = 0.24) but long-lasting treatment effects for family-based treatments (the effect was evident on

average 2.5 years after treatment) compared to usual individually focused community services. A meta-analysis by Weisz, Hawley, and Doss (2004) also indicated that family-based treatments have beneficial effects on youth's mental health problems such as anxiety, depression, attention-deficit/hyperactivity, and conduct disorder.

Family-based treatments have been successfully used with adult offenders too. Datchi and Sexton (2013) examined the effect of Functional Family Therapy (FFT) with adult offenders. Offenders who completed the FFT experienced significant improvement in psychological and interpersonal functioning, reported fewer symptoms of distress, less family conflict, and higher levels of family cohesion and organization. The FFT group had significantly reduced risk of reoffending compared to offenders receiving traditional probation services. NICE Guidelines (2015) also suggest that family intervention for adults with psychosis and schizophrenia helps these adults cope and reduces stress.

Governments have recognised the value of supporting offenders' families (Sutherland & Wright, 2017; Criminal Justice Family Support Network, 2015) and organisations have been created to provide support to affected families (e.g., Barnardo's Cymru; Families Outside; Support for families and friends of prisoners). Studies have also examined the unintended financial, emotional and social costs of imprisonment on offenders' families (Breen, 2008). Offenders' children and partners report that they often feel punished, stigmatised and isolated (Arditti, 2003; Bakker, Morris and Janus, 1978; Codd, 1998; Mauer & Chesney-Lind, 2002; Murray & Farrington, 2008).

Only one study to date has examined the impact of offending on the main

caregiver. Sturges and Hanrahan (2011) interviewed 27 mothers of offenders. Mothers reported physical, psychological, relational, social and economic effects, in addition to feeling stigmatised and isolated by family, friends and the community and internalising blame. They also reported that the offence was not an event but a continual process of adaptation and adjustment, lasting years and pervading every aspect of their life, effectively a 'life sentence'.

Main carers of people with severe mental health problems report similar experiences of stigma, isolation, psychological, relational and social burdens (Vermeulen, Lauwers, Spruytte, Van Audenhove, Magro, Saunders, & Jones, 2015).

The association between poor mental health and offending behaviour is well established. Approximately 25% of offenders have some mental health problem (Wallace, Mullen, Burgess, Palmer, Ruschena, & Browne, 1998), making it very likely that family members of people with mental illness may also come into contact with the legal system. Therefore, it would be important to examine the psychological impact on the family members of men admitted to a medium-secure facility as a result of offending and related mental health problems. This is all the more important as this group of carers is unique. Whereas the impact on carers of people with mental health problems has been studied to some extent, there is only one study on the impact of carers of offenders and no studies on the double impact on carers of people with coexisting mental health and offending problems. Completing my placement in the Assertive Outreach Team also gave me the opportunity to witness first-hand the psychological impact on carers of men with both severe mental health and offending difficulties and the lack of services and support for them.

As previously discussed, the support families offer offenders and relatives with mental health problems leads to better outcomes for the latter, therefore it is important to understand the impact on the carers in order to better address their needs. In addition, increased knowledge and understanding of the impacts on family members will have implications for policymakers and stakeholders who can implement programs aiming to break the isolation, stress and stigma encountered by caregivers, mentally ill people and offenders. Programs that enhance resilience in carers could also be developed, which may prevent crime and further psychological problems (Ferguson, Harms, Pooley, Cohen, & Tomlinson, 2013).

The present study was an exploratory, small scale study so, in order to reduce heterogeneity of the sample, the focus was on family members of male offenders admitted to medium-secure facilities. Most people admitted to secure facilities are men (Gibbons, 2013) and more studies have been conducted with male offenders thus making comparison with previous research easier. The types of crimes and the types of mental health problems experienced by male and female offenders are generally different (Denno, 1994; McManus, Bebbington, Jenkins, & Brugha, 2016) and therefore the psychological impact on their family members might be different. Therefore, the aim of the present empirical study was to explore the psychological impact on the family members of men admitted to medium-secure facilities as a result of offending and mental health problems using Interpretative Phenomenological Analysis (IPA).

Method

Design

The present qualitative semi-structured interview-based research was conducted with a purposively selected sample of six participants having a male relative admitted to a medium- secure facility as a result of offending and mental health problems. Given the sensitive nature of the topic, ethical guidelines were carefully considered and incorporated in the design of the study. These are described in the Participant Information Sheet (Appendix Two).

Rationale for the use of IPA

Interpretative Phenomenological Analysis (IPA) was chosen given the phenomenological and idiographic focus of the methodology that allows the detailed study of participants' experiences and how participants make sense of these. The ideographic focus of IPA allows us to examine the unique and particular experiences of each family member, from which themes emerge. The phenomenological focus of IPA allows us to explore in detail what it is like to be a specific person who has this particular experience, that is, what is it like to be a family member who has a relative with serious mental health and offending behaviour and who has been detained in a medium-secure facility. IPA stresses the subjective nature of the participants' and the researcher's meaning and sense-making (Smith, 2004) and this makes this approach particularly suitable to the present research question. Other qualitative methods were considered carefully but IPA was chosen for the above reasons.

Sample size

The objective of IPA research is aimed at capturing the experiences of participants, so a sample size of five to twelve participants has been suggested as appropriate (Smith & Osborn, 2003). Furthermore, for doctorate-level research, a guide of four to ten interviews has been suggested (Smith, Flowers, & Larkin, 2009). Taking this into consideration, this study aimed to interview between six to ten participants (Smith, Flowers, & Larkin, 2009).

Materials

Interview schedule

A semi-structured interview schedule (Appendix Three) was developed by the principal researcher (IL) in collaboration with the academic supervisor (AC) and after consulting the relevant literature to identify the important topics. The schedule flexibly guided the interviews and facilitated open dialogue. It consisted of five open-ended questions covering five topics: (1) relationship with the detained relative and family's social environment; (2) the main caregiver's reaction to the offence; (3) psychological impact on the main caregiver; (4) coping and support of the main caregiver; (5) future expectations of the main caregiver. Each question also included prompts and probes to clarify meaning and elicit examples if necessary.

Demographic Information sheet

Information regarding participants' relationship with the detained relative and number of months since he has been detained in a medium-secure facility was obtained during the interview. Furthermore, if the information did not emerge during the interview, participants were asked to provide brief demographic information for

themselves (age, ethnicity, occupation) (Appendix Four) and their relative (age and ethnicity), however, this was optional (Appendix Five).

Participants

Six participants were recruited through NHS professionals working with offenders' families in medium-secure facilities which provide support to families of men admitted to these facilities.

Principal criteria for inclusion were that participants were aged over 18 years and had a male relative who was detained in a medium-secure facility. In addition, participants must have had close contact with their relative within the 12 months prior to detention. The purpose of establishing that there was a regular amount of contact between the relative and the family member in the build-up to the admission was to ensure that there was likely psychological impact on the family member and a relationship experience. In line with similar research, the minimum level of contact was established as at least 2 weekly contacts (face-to-face, telephone, or other) on average during at least 6 months in the year preceding the admission.

Demographic information collected for family members and their relatives is summarised in Table 2.1. Participants were four mothers, and one aunt and one uncle-in-law of the same nephew. The aunt and the uncle-in-law described the relationship with their nephew as 'close' and stated that they were the only close family he had and the only ones who visited him in the medium-secure facility. Most participants self-identified as White British (5), female (5) and employed (3) or retired (3). They were between the ages of 52 and 75 years (Mean age 67 years).

The relatives have been detained in a medium-secure facility between 1 and

5 years (Mean: 2.6 years). They varied in age between 24 and 54 years (Mean age 36.6 years). Participants identified their relatives as White British (4), Black Caribbean (1) and mixed White British and Black Caribbean (1).

Table 2.1

Demographic Information of Participants and their Relative

PARTICIPANTS						RELATIVE			
Pseudonym	**Gender**	**Age (years)**	**Ethnicity**	**Occupation**	**Relationship with detainee**	**Pseudonym**	**Age (years)**	**Ethnicity**	**Time since detained in medium-secure facility (years)**
Gemma	Female	52	White British	Employed	Mother	Sean	24	Mixed White & Black Caribbean	2
Catherine	Female	73	White British	Retired	Mother	Mark	38	White British	1
Anna	Female	65	White British	Employed	Aunt	John	33	White British	5
Peter	Male	75	White British	Retired	Uncle-in-law	John	33	White British	5
Liliane	Female	62	Black Caribbean	Employed	Mother	Al	34	Black Caribbean	4
Rebecca	Female	75	White British	Retired	Mother	Bob	54	White British	1

Procedure

Three clinical and research psychologists from the academic team at the University of Birmingham independently reviewed the study protocol. Upon reviewing and approving the study and all supporting documents, The University of Birmingham's Governance Department provided sponsorship for the study (RG_17-233, Appendix Six). The research has also been reviewed and discussed by the relevant NHS Foundation Trust's Committee. Ethical approval for the study was granted by the NHS Research and Ethics Committee (18/WM/0181; Appendix Seven).

Eligible participants were identified by members of the NHS care providers' team working with offender's families in medium-secure facilities for men. Dr Mantia-Conaty, in her role of field supervisor, facilitated contact with the NHS members who were qualified professionals including psychologists, psychiatrists, nurses, occupational therapists, and social workers. The primary researcher (IL) met with or contacted the NHS professionals and provided them with an outline of the study explaining its nature, purpose and procedure, and an information sheet to be distributed to eligible participants. Participants who were interested in participating left their details with the NHS team and were contacted by the primary researcher (IL). This approach was selected to minimise pressure felt by people to participate. Once contact was established, participants were provided with the opportunity to discuss participation in detail. For participants wishing to continue, a suitable time, date and interview location were arranged. Participants were forwarded information sheets detailing in simple terms the purpose, methodology, risks and benefits of participation and were encouraged to

take a minimum of 24 hours to decide on participation. The informed consent form (Appendix Eight) and the interview schedule were posted prior to the interview so that participants were aware of the topics to be covered and so that they would have the opportunity to identify areas they may find difficult to talk about. The primary researcher met with participants in their preferred interview setting, which was either the participant's home or an office booked for the purpose of the interview. During the interview, participants were provided with the opportunity to ask questions and if they wished to continue, written informed consent was obtained. The consent form informed participants that their participation was voluntary; that they could withdraw at any time; that if any risk was disclosed appropriate University guidelines would be followed; that interviews would be audio-recorded; and that data would be anonymised. To minimise potential distress, participants were also told that they can stop the interview at any time and that the interview could be divided into two shorter ones and that they can request short breaks during the interview.

One individual interview was conducted with each participant. Four interviews were conducted in the participants' homes and two in an NHS office. All interviews were audio-recorded with consent and assigned a unique identification code so that no participant could be identified. The interviews took place between November 2018 and February 2019 and lasted between 30 minutes and one hour and 40 minutes. They were guided by the semi-structured interview schedule. At the end of the interview, participants were given the option to complete a brief demographic information sheet for themselves and their relative if this information was not obtained during the interview. Participants were thanked, debriefed and

offered information of support organisations.

All interviews were transcribed verbatim and identifiable information was removed or modified to preserve anonymity.

Analysis

The generated transcripts were analysed manually using Interpretative Phenomenological Analysis *(*IPA) methods and were flexibly guided by the procedure outlined by Smith, Flowers and Larkin (2009).

The first stage of analysis involved reading and re-reading the transcript, listening to an audio recording of the interview to re-familiarise and engage with the data. The next stage involved line-by-line coding, noting significant or interesting linguistic, descriptive or conceptual observations in the text, with a clear focus on the meaning of these observations to the participant (Larkin, Watts & Clifton, 2006). Next, the initial coding was condensed into phrases (emerging themes) that captured the essence of significant sections of the transcript (Appendix Nine). Connections/patterns between the emerging themes were sought and clustered together (Appendix Ten). Clusters of themes were then given names to represent superordinate themes. Next, a table representing the development of each superordinate theme was created including a list of emerging themes, direct quotations from the transcript detailing the line and page where they could be found (Appendix Eleven). These guidelines were followed for each transcript in turn. The final stage involved looking for patterns across tables generated for each participant, selecting, reconfiguring and discarding themes and then generating a master table of superordinate themes, listing corresponding emerging themes and instances/quotes and line numbers for each participant (Appendix Twelve).

To reduce researcher bias, the academic supervisor oversaw each stage of analysis, in order to ensure no data was under or overrepresented when identifying emerging themes for an individual and across transcripts.

Reflexivity

In IPA analysis, the researcher offers an interpretation of the way participants themselves make sense of their experiences. This is known as a 'double hermeneutic' (Smith, Flowers, & Larkin, 2009), meaning that the researcher is making sense of participants' making sense of their experience. The interpretation offered by the researcher is influenced by her experiences, preconceptions and interests and these need to be acknowledged, as well as kept in mind for the duration of the study (Willig, 2008). At the time of the present study, the researcher (IL) was a third-year trainee Clinical Psychologist who was on placement working with service users with psychosis, some of which were detained in forensic non-acute inpatient settings. The researcher also met with some of the service users' carers as part of her work. Prior to her psychology training, the researcher worked in a prison with detainees who experienced mental health difficulties.

Procedures were followed to minimise the possible influence of the researcher's preconceptions on the interpretation of participants' experiences. A reflective diary was kept throughout the analysis allowing the researcher to note reflections, observations, opinions and feelings to the content analysed (Ortlipp, 2008). In addition, the researcher listened and re-listened to the recordings in order to stay close and grounded in the transcripts. The researcher also received regular supervision throughout the research process and attended an IPA peer support

group throughout the analysis and write up period. These allowed to minimise bias, enhance transparency and credibility of the interpretation of the transcripts and an equal representation of the data.

Results

Four superordinate themes emerged from the analysis. These were underpinned by nine themes, one of which was further subdivided into two subthemes. The themes are diagrammatically represented in Figure 2.1.

Participants' accounts were similar in the language they used and the way they recounted their experiences. All accounts appeared to proceed in chronological order, like a 'drama plot', starting with a prelude, moving through the build-up and the culmination, and ending in tentative alleviation. In a drama plot, the prelude puts the person's experience in context. The build-up describes the events that lead to the problematic issue or the conflict, and therefore it is the most important and central element in the process. The culmination is the point when the issue reaches its peak. The tentative alleviation is the final process when there is a change for the better or adaptation, i.e., there is an improved experience when compared to the build-up phase although the issue may not have and may never be resolved.

In the present analysis, it was felt that the four superordinate themes mapped well onto the four parts of a drama narrative and hence this metaphor was used in order to capture this and aid the reporting of results. The first superordinate theme, the prelude, gave the background context to the story of the participants. It described the deterioration participants witnessed in their relative, how they tried to make sense of this change and to cope with it and the powerlessness they felt about helping their relative. The second superordinate theme reflected the build-up participants experienced dealing with the mental health and justice systems that they felt let them down. This theme covered their and their relative's long journey through the mental health and justice systems, the family member feeling angry and

frustrated with the system and the feeling that their relative has been victimised by the system. This build-up led to the third superordinate theme, which was the culmination. The culmination was the point where conflicts with the system reached a peak and participants were at their worst. Here participants spoke about the psychological and physical impacts they experienced due to their relative's mental health and offending behaviours, including the sense of threat they felt due to their relative's aggressiveness, unpredictability and propensity for violence and their worries about their relative's future. Participants also spoke about the psychological impact on the wider family. The tentative alleviation, the fourth superordinate theme, described family members' acceptance and adaption to their relative's situation, but unlike in a true drama plot, this was experienced as a continuous and endless process because although all family members experienced a release of tension and anxiety, and to a certain degree a return to normality, the conflicts with the system they experienced were never completely resolved.

Each superordinate theme, associated themes and subthemes will be presented in turn with selected supportive illustrative verbatim quotes. All quotes are presented in *italics* and three dots situated in quotes indicate that some text has been omitted for brevity. Details have been removed to preserve anonymity. On few occasions, capitals are used to stress the depth of feeling expressed by participants. Details of participants that contributed to the development of each theme are summarised in Table 2.2.

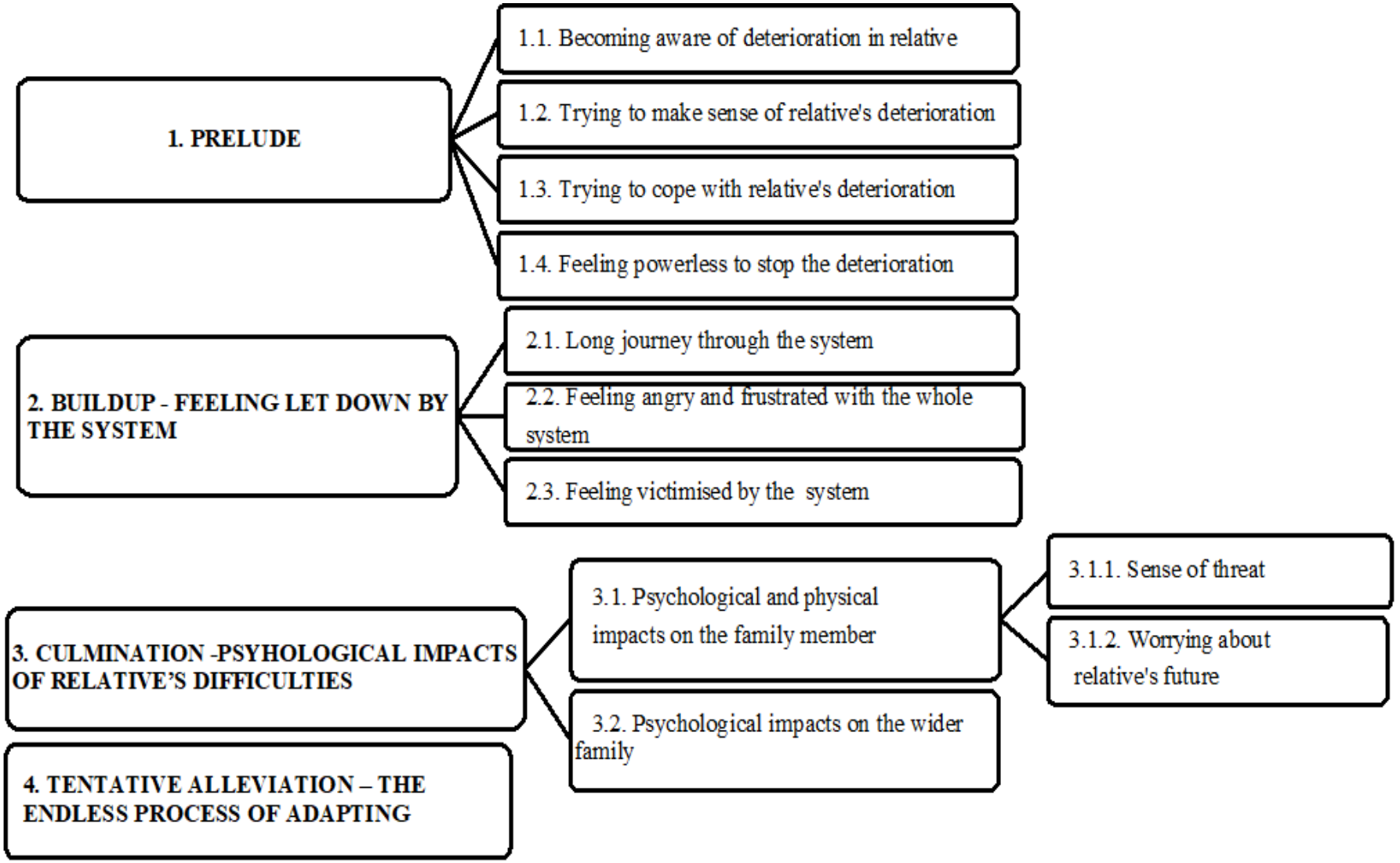

Figure 2.1 Diagrammatic summary of superordinate themes, associated themes and sub-themes.

Table 2.2

Details of participants that contributed to each superordinate theme, associated themes and subthemes.

	Gemma*	Catherine*	Anna*	Peter*	Liliane*	Rebecca*
1.Prelude	√	√	√	√	√	√
1.1 Awareness of deterioration in relative	√	√	√	√	√	√
1.2 Trying to make sense of relative's deterioration	√	√		√	√	√
1.3 Trying to cope with relative's deterioration	√	√			√	√
1.4 Feeling powerless to stop relative's deterioration	√	√		√	√	√
2. Feeling let down by the system	√	√		√	√	√
2.1 Long journey to getting help	√	√	√	√	√	√
2.2 Anger and frustration with the whole system	√	√		√	√	√
2.3 Feeling victimised by the system	√	√		√	√	√
3. Psychological impacts of relative's difficulties	√	√	√	√	√	√
3.1 Psychological and physical impact on the family member	√	√	√	√	√	√
3.1.1 Sense of threat	√	√	√	√	√	√
3.1.2 Worry about relative's future	√	√	√	√	√	√
3.2 Psychological impact on the wider family	√	√	√	√	√	√
4. Endless process of adapting	√	√	√	√	√	√

1. Prelude

This superordinate theme puts the participants' experiences in the context of the events that lead to the build-up theme. It captures family members becoming aware that something was wrong with their relative, leading them to feeling confused and unreal and to trying to make sense of what was happening. This theme also captures family members trying to cope with their relative's deterioration by continuing to support him and to seek help for him but feeling powerless to obtain the necessary help.

1.1 **Becoming aware of a deterioration in relative** *"He turned into somebody I didn't know anymore"*

All family members noticed a change for the worse in their relative's personality and way of being with them and others which they frequently experienced as a loss of a person they knew and cherished and as the emerging of an aggressive stranger, or a sinister transformation, *"… his personality was totally changing from a nice down to earth, loving, caring son to quite a cold nasty person." (Gemma)*

Gemma proceeded to explain how her relative transformed from a good-natured young man to a mean, angry, aggressive and difficult to be around person.

"He was … happy, bubbly young man … had loads of close friends. … at school, he did really well, he did a lot of sports, did rugby, did kickboxing. … excelled in sports .... He was a high- flyer of a lad ... during his late teenage years … no problems, never had any real incidents ... No fighting… he went to uni … and then after the first year, I just noticed little changes with him … he'd be quite rude in the way he

came across to me … he was like saying things to me to try and hurt … where he was very polite and … he always used to say "I want to make mum proud"... Try to put me down, like I was stupid. … And he just… he had a smirky way about him that was quite horrible! …. And I thought this is not Sean … Sean isn't rude like this … This is … this is somebody I'm not really knowing … It was a total change of personality. Really quite nasty. You know quite scary." (Gemma)

Rebecca echoed Gemma's sentiment when she described the transformation of her relative and her difficulty to recognise the good and caring person that she always knew in the aggressive man she was facing.

"You know, he was very good, very good lad. … He was very caring and very good. … He's never used to wake up in a bad mood when he was a little kid. … He wasn't hard to bring up. When he was growing up, when he was little, he was never aggressive, and he never was aggressive as a teenager ... He turned into somebody I didn't know anymore."

Most family members had a hard time to reconcile how somebody who was such a "*polite and lovely"* person could transform into an aggressive man who would find himself detained in a medium-secure facility for a serious offence and for several years (Liliane).

"He was the only one, he would come and eat my food and say 'Thanks mum' … he was a lovely son … He is the most decent of the whole lot, you can ask anybody …

a lovely boy, always saying 'please' and 'thank you'. He was always very polite." (Liliane)

Similarly, Catherine also found it hard to reconcile how her son could be *"… a very kind-hearted boy … Very soft especially with women"* and physically assault his brother and his father.

Frequently the relative's deterioration was gradual and progressively getting worse. Liliane, for example, described how her son started to give her odd answers, then laughed by himself, then became argumentative and aggressive with his brothers and then he began to experience visual hallucinations, and this was over a span of 15 years.

The majority of the relatives have had long-standing mental health and legal difficulties, spanning 15-20 years, and have been in and out of mental health institutions and/or prison. Despite that, family members noticed a significant mental deterioration and increased aggressivity in their relative before he was detained in a medium-secure facility. Catherine recalls that her son Mark assaulted one of his brothers and his father, something that he has never done prior to being admitted to a medium- secure facility, despite his long-standing mental health and legal difficulties. She also observed a marked deterioration in his mental state which was more significant than previous times.

" *… last August when all of a sudden he started texting me. … the texts were weirdish and I wasn't sure what state he was in so I was very careful what I replied. … I was concerned about him. Ahm, because some of the things he was saying, I*

thought he was paranoid, he got, he was paranoid and you could tell that things were not quite right … I knew that he wasn't right!" (Catherine)

1.2 Trying to make sense of relative's deterioration

Faced with their relative deteriorating in front of their eyes, family members tried to make sense of this transformation. Every family member had a different explanation for their relative's deterioration. Some attributed it to a mental illness, "*He has schizophrenia you see, he has schizophrenia and you could see that he was going nowhere, that he was gone …" (Anna),* others looked at the possible distal causes for their relative's deterioration and believed that it was due to the accumulation of adverse life experiences from an early age. Rebecca for example, attributed her son's deterioration to him having been bullied, assaulted and to the impact her and his father's mental health problems may have had on him.

"He was bullied at school, unmercifully right from the day he started school. He was attacked in the street, had the police involved and he yes, he's had it rough. He's had it really rough since he was this high bless him! … He suffered a lot since he was a child really. It started at school and then when his father becoming ill that made it worse and you know, then with me having postnatal depression it must have felt like his whole world falling apart." (Rebecca)

Peter also attributed his relative's deterioration to the neglect and the sexual abuse he suffered as a child, *"Of course because they were neglected, they started to get into trouble."*

Other family members, like Liliane, attributed their relative becoming unwell to him starting to smoke cannabis, to destiny, to bad luck and to this experience being a test of her personal strength.

"…but then he started smoking and everything started to change. … He's a sensible boy. Very sensible. He was very bright. I think if he hadn't started smoking, he might have been alright.…", "He just had bad luck in his life.", "… in life things happening you've got no control over. That's it. If it's gonna happen. It's gonna happen. And I just think maybe it was his destiny. I believe everything that happened to him was meant to be and nobody or nothing can change it if it is going to happen. But to me I'm thinking it's a test that I'm learning coming at the other end I think for me. To see how strong you are or how weak you are. What is gonna make you, is gonna break you. He's broken me big time." (Liliane)

Gemma, similarly, attributed her relative becoming unwell to him smoking cannabis, which she believed triggered memories of sexual abuse she was unaware her relative had experienced as a child.

"… he was getting flashbacks, memories and he never had them before he had the draw. You know the marijuana and he didn't have them before…And I just can never forgive that and how he's paid for that and how he's got ill. … I think that was the trigger. I think that was the trigger of, you know, smoking the draw, and memories coming back it just overwhelmed him, he couldn't cope."

However, Gemma also conceded that her relative's illness played a role as well, *"… I know it's not the only thing, the condition he's got but you know it's part of it".*

1.3 Trying to cope with relative's deterioration

While family members were observing a deterioration in their relative and trying to make sense of it, they were also trying to cope with what one could describe as a sinister transformation by adapting to their relatives' needs. They coped by actively seeking professional help for their relative, and by providing material and emotional support to him.

Most family members continuously and tirelessly sought professional help for their relative when they noticed a deterioration. Gemma, Catherine and Liliane described this long and arduous process and how they kept being turned away or redirected from service to service in what felt like a vicious circle. They phoned family practitioners, hospitals, various mental health services, and even the police.

Family members also provided material support such as housing, food, and safety. Gemma's son Sean, for example, lived with her but when she became too scared of him and he had to leave her house accompanied by the police, she continued to support him by providing him with food while he was living at his brother's, *"I was giving food for him. I was still supporting him…" (Gemma).* When Sean's behaviour made it no longer possible to live with his brother, Gemma made sure Sean's car was paid so that he could live in it.

"… Sean still got his car and we paid for Sean's car. We made sure he had that. If anything, he had the car. So at least he had somewhere where he could be.

You know, just to keep, still trying to keep a roof above his head basically." (Gemma)

When it was too dangerous for Sean to live in his car in the summer and he had absconded from hospital, Gemma adapted the conservatory for him although it was against court orders for him to live in her house. Gemma had 'reinforced' the house because she was still afraid of Sean, but she still wanted to support him. *"So, he could be in the conservatory … and I could pass food through the window in the kitchen to him because it was so hard. … I'd give him food. I'd pass it through the bars. It was awful."*

Similarly, Rebecca's relative lived with her but due to him turning the house into a complete mess, his erratic behaviour and his drug use, she had to leave the house. When her son was evicted from the family house by the landlord, he was given council flats, which Rebecca furnished with beds, carpets, TVs, cleaned them, and paid his bills but her son kept demolishing them and finding himself in the street because no one could live with him and he could not live on his own.

"I used to pay his bills to make sure they got paid." (Rebecca)

Catherine also helped her son with food and with paying his rent *"…he said, 'Could you help me out with food?'. We lived a long way away, but I did go and I took food and left it in his hallway [because he did not want to let anyone in, in his flat]..."*

All family members also provided moral support. This is illustrated by Anna and Peter.

"But as I said he's got nobody. He's ABSOLUTELY got NOBODY apart me and

Peter. … He can feel that he is loved, you know. He's got that." (Anna)

"… Nobody ever visited and for me for him to be alone and never have a visitor we just couldn't do that. We needed to give him some sort of hope that somebody cared" (Peter)

1.4 Feeling powerless to stop the deterioration: *"You are fighting a losing battle"*

Despite family members being aware that something was wrong with their relative and trying to cope with and adapt to their relative's deterioration, they felt powerless to stop it.

"We could see what was going to happen with the kids, but we can't prevent it. I mean we cared about them." (Peter)

A lot of this sense of powerlessness stems from the family member trying to find the appropriate help for their relative but their relentless efforts being unsuccessful.

"And through all of this, I was trying to get help. I was ringing up [Service Z]. I was ringing up the street triage team, the homeless team, everybody. Trying to get somebody to come and see him. I'd be going 'Something is wrong. You need to speak to my son. Something is really wrong!' … This went on for about a year trying to get someone to listen. Nobody would listen to me. I went to the GP's. … This was the GP's 'Oh, if he is not well, he'll come and see us.' And I kept going, 'He's not well. I can tell you that for a fact. Something's wrong but he ain't gonna come and see you because as far as he is concerned, he is okay.' I said, 'The whole family is*

falling apart, nobody's helping, he's in the car. … And nobody's helping us!' And that's what hurt me more, that nobody would listen to us. Nobody would take any notice. Doctors, even the police … No one! We tried everything, you know. Everybody. We went to police, we told everything. … I had to watch and wait for my son to get arrested. ... [I] had to stand in the dock cry like this, begging for help and they did nothing …" (Gemma)

Other family members also echoed a similar sense of helplessness.

"… you don't know who to turn to at the end of the day…" (Liliane)
"You are fighting a losing battle. … I just felt helpless … I'm not trying to blame anyone but looking for a level of responsibility." (Catherine)

Furthermore, when asked if things could have been done differently, Catherine felt that she had done all that she could when her son began to deteriorate but services would not listen:

"I am not sure we can change much. We've done the best we can, and I've done the best I can. I've gone to the authorities, the mental health team and they've ignored me. … I don't think what else I could've done? … I did all I could when I knew what happened with him."

2. Build-up: Feeling let down by the system

This superordinate theme captures the accumulation of events that lead to the culmination. It describes the family member's and the relative's long journey through

the mental health and justice systems before receiving the necessary and appropriate help. It captures the feelings of anger and frustration this journey stirred in the family members as well as the feeling of being victimised by the system because appropriate help was unavailable early on which led to the escalation of their relative's mental health problems and to him being sent to a medium-secure facility.

2.1 Long journey through the system

All family members described the journey of their relative as long and difficult, with a lot of ups and downs and spanning years, from 4-5 years to nearly a lifetime, 20-25 years.

"… we've had a real nightmare in the last few … well the last 5 years, absolute nightmare!" (Gemma), "Mark's had 20 year plus hmm, history of mental health issues. … Not been an easy ride…. He was always under the medical health team." (Catherine)

The relatives' journeys involved difficulties finding the right service for them, numerous engagements and disengagements with services, hospitalisations, troubles with the law, living on the street, and imprisonments. Relatives also experienced a gradual deterioration before being detained in a medium-secure facility.

Liliane described her relative's long journey through the mental health system, which spanned 15 years:

"They told him that they [Service A] were gonna put him in a hospital for a month. … When he was about 20 that's when it happened. And he got put into Hospital A*. Then came out, was okay, then again was put in Hospital B*. … He went into Hospital C*. He went into a place over in X*. He's been in quite a few places. … Al's been in and out, in and out of hospital. But the last time he came out, it was 4 years before that incident happened. ... That's the longest that he's been out before it happened."*

For some family members, the mental health problems of their relative were compounded by imprisonments. Relatives frequently found themselves in prison because they did not receive the appropriate help they needed for their mental health difficulties from the appropriate services soon enough.

"Many times in prison. Many times. In and out. In and out. Which is a nonsense! Two weeks here, 4 weeks there and they chuck him straight back out onto the street. …. he was always in prison." (Rebecca)

"John's been locked up now for 13-14 years. He was in different sections, yeah, different prisons…" (Anna)

"Was in and out of the nick. … Has been in jail 11 years now." (Peter)

2.2 Feeling angry and frustrated with the whole system

The long journey through the system led to strong feelings of anger and frustration in family members which appeared never to resolve. Talking about their experiences during the interviews stirred up a lot of these feelings and some family

members cried out of anger.

A major source of frustration and anger for family members was that they were not listened to when they said that their relative was unwell and in need of urgent help. Gemma and Catherine illustrate this:

"I said, 'From day one since all this has been going on, I told you something was wrong! I've told everybody something is wrong! This is not Sean and none of yous has listened to me! None of yous!' … I said, 'I kept telling you and nobody did anything! No one!'" (Gemma) "NOBODY LISTENS and that's, I think that's a lot of frustration, of upset and of anger." (Catherine)

Another frustration which is related to the previous point was family members having had to repeat their story over and over again, but it falling on deaf ears. This made family members feel that they were not taken seriously.

" Oh, has nobody been listening!? Even the professionals here. They are not listening! … I feel like I was constantly repeating the same things all the time but so desperate for help but different people and I had to keep going over the same things and this really drove me crazy but I thought, I'll just keep on because I need help." (Gemma)

A lot of the anger was also driven by a feeling of despair and exhaustion from fighting to get help while seeing one's relative deteriorating evermore.

"I was ringing the doctor's all the time going, 'Please someone come and speak to

him! Please come out.' And one day I just had enough. I'd had enough … I said, I have asked and asked doctors for help nobody will help me, and I was shouting on the phone. I got to a point where I had enough. And I went 'I had enough!' I was crying. … I said, 'I am watching my son die'!" (Gemma)

Family members were angry at the mental health and justice systems for not doing anything to help their relative. They were frustrated with the mental health care system for not recognising how gravely ill their relative was. Speaking of mental health services' failures, Liliane, Catherine and Gemma expressed their frustrations in the following ways:

"Al was really sick them days … The social worker, you know what really hurt me? That Friday before the incident happened the social worker phoned me and said, 'Oh, Mrs X, we've got to change Al's medication but you've got nothing to worry about' and in less than a week he, he, he was locked up for, for, for the death of somebody really. And it really doesn't make any sense! That don't make no sense to me. Doesn't, that didn't make no sense. And then the policeman pushes me into my house and asks me all these questions …" (Liliane)

"I was angry. I was upset. I was frustrated! Because I couldn't believe that any competent health authority would discharge someone with a 20-year history of mental illness. … everybody missed the signs … and he should have never ever been discharged! I've got an issue with that, but you can't get anywhere with it … The crisis team said no, he is fine. … Everybody said he is fine and I said, 'HE IS NOT FINE!' " (Catherine)

"… they came [the CRISIS team] and they was like, I couldn't believe their attitude at all really! The one woman was going, "Ouuh, he's ok." I said, "He's not ok! Can't you smell him when you get in the car?! Can't you smell him?! No? He stunk! He absolutely reeked!" (Gemma)

Family members also expressed their frustrations with the complete lack of support from the justice system:

"There's no support for them from prison and that's another thing they need to sort out." (Rebecca)

"It's not good enough. It's not good enough. They need, there's no way even when we were dealing with the courts, I was in contact with ayh, woman's aid support worker … told her everything. ... She told the magistrates and they still done nothing. She said that they said to her their hands are tied. Their hands are tied?! They could've ordered a section ... They could've ordered that. I am in such a state. … I know my son is ill and they could see that it was upsetting me, and they did nothing! They did nothing!" (Gemma)

Some of the anger and frustration of family members were related to their relative not receiving timely mental health help or being discharged from mental health services, which led to them being detained in prison and having the added burden of having a criminal record, in addition to serious and long-standing mental health problems. Family members were worried about the impact on their relative of

having a criminal record.

"And I am still very bitter and annoyed and angry with the health care system in X … I've got nothing good to say about them, I'm sorry. …I am 99% [certain] that it [prison] could have been avoided and now he has a record and for whatever reason which is going to make a difference for the rest of his life!" (Catherine)*

"So they really could've messed up his future. I hope that they haven't. …They could wreck people's lives all for the sake of being unwell." (Gemma)

A lot of the anger and frustration family members experienced were related to not receiving information about their relative from services. Many family members were frustrated that they were not informed when their relative was discharged from hospital or prison and that as a result, their relative found himself on the street, vulnerable and without any support.

"…. what they [the prison authorities] did was they let him go out onto the streets without anywhere to go to, any address and they just let him out." (Gemma)

This lack of communication made family members feel dismissed and angry about not having the opportunity to have a say and to be involved in their relative's care. Catherine was one family member who was not informed that her relative was discharged from hospital and that he was on the street. She spoke about spending one Christmas night outside looking for him and worrying if something bad has

happened to him.

"Just the whole feeling of frustration and lack of cooperation, lack from everybody being involved in anything and being told anything. … Surely you can divulge some information! … Basic human rights for us as parents! … The law should change! … The levels of frustration and upset because of that…" (Catherine)

This was a continuing worry for some family members who continue to feel frustrated and angry at the system and failed by it because they received no or limited information about their relative and their relative was held out of area.

"They don't tell you anything you see. So that's all I know. And I don't know who to ask because they don't want to tell you anything on the phone. … It doesn't help me you know knowing, you know what's the possible outcome for my son. … It's difficult to make an appointment when I'm so far away because I don't know if I can get there." (Rebecca)

Family members were very angry that they and their relative had to go through such a nightmare in order to obtain the necessary help.

"And that's what angers me. He's got through that! ... And then I'm going through all that …" (Gemma)

2.3 Feeling victimised by the system

Family members felt victimised both by the health and the criminal justice systems. Rebecca recounted how her relative was frequently thrown out of hospital in the middle of the night, without money or transport and in the wintertime. She cited how one winter Bob was living on the streets, he fell asleep and fell into the river. He came out but was wet and freezing so he found a phone and called an ambulance. He was taken to hospital but was discharged in the middle of the night because there was nothing wrong with him and because staff felt he just wanted a bed for the night, *"It's horrific what happened to Bob…" (Rebecca)*

Peter, similarly, felt that his relative was victimised by the prison system.

"They victimised him [in jail] you know what I mean. …. They need to be helped in prison. People's lives ruined because they didn't get that bit of attention. … Nobody should be locked up for life." (Peter)

Liliane also spoke about the poor treatment of her son in prison:

"When I went over there I say, 'Where's your shoes?' 'Momma I have no shoes.' … He had nothing on. Naked in the cell just like the day he was born. He didn't deserve all them treatment."

Catherine described how her son had no medication for a whole year, no mental health support and how he became paranoid and aggressive, was on the road, was hit by a car and lost a lot of weight in the one year prior to receiving appropriate help, *"He wouldn't have been there [prison] if he hadn't been discharged from the system altogether because it is so wrong to do that."*

People with mental health problems not only were not being helped by the health care system but were given criminal records and traumatised in prison.

"So I had to watch my son, he was at university, he was outgoing, had a great life ahead of him and taken to prison cell for not even charged, nobody went into the prison and offered him any help, nobody in the prison assessed him, nobody went to speak to him… they treated him awfully and wrong. …Because he has to live with that that record now, that police record. … seeing him in a prison and the chains … That's what affects you more than anything." (Gemma)

Some family members still felt victimised by the system. Rebecca's son was moved to a hospital for tests from the medium-secure facility he was in and establishing communication with him was not easy and his family could not visit because he was out of area.

"I phone him as much as I can [in the hospital] but the phone is horrific trying to get through where he's moved to now. It'll be a couple of days trying to get through and I think that's bad because when you're ill and you are far away from your family, you need to be able to communicate and you can't communicate…"

3. Culmination: Psychological impacts of relative's difficulties

This superordinate theme captures the point where the psychological and physical impacts on family members reached a peak and they were at their worst. These impacts were the result of both their relative's mental health and offending

behaviours and the difficulties created by the system in the process of their relative receiving appropriate help. The impacts on family members included the sense of threat they felt due to their relative's aggressiveness, unpredictability and propensity for violence and their worries about their relative's future. There is also an associated theme of the psychological impact on the wider family who was affected as well.

3.1 Psychological and physical impacts on the family member

Family members described feeling a variety of complex emotions such as sadness, anxiety, guilt, shame, and isolation due to their relative's issues. Some family members were more impacted by the mental health problems, others by the offending problems of their relative and some by both. They described an impact in all areas of their lives, such as their daily life, work, social relationships, and in general their ability to cope.

Most family members described feeling depressed and anxious as a result of their relatives' offending behaviour. Liliane, for example, was very tearful when she described the emotional impact on her of her relative's offence, arrest and subsequent admission to a medium-secure facility: *"… My anxiety was just bad. I'm on the bus, I'm crying. If anybody asked me about him, I'm crying … Every day I'm crying. I am still crying now. … I got to a stage where I didn't want to go nowhere, just go to work and come back and stay in the house. ...I liked going out. … I liked to go and purchase clothes and stuff you now and then for a while I just didn't go anywhere for a long time. … So, I was home for a while, you know. Every time I think about him, it just, just hurts me. I go to bed in the night-time and I can't sleep. You're thinking, when your child is young and they are growing up you don't know what they are going to turn up to be like and I didn't expect him to be where he is*

today. It hurts."

Rebecca described similar psychological impacts on her due to her relative's mental health issues, *"Just you know very down all the time…".*

Catherine described the double impact on her own mental health of her relative's mental health and offending difficulties and of him going missing before she found out that he was in prison. Speaking about the time her son went missing,

"I felt suicidal…. Sometimes I was so upset, I can't take this. And that's dreadful but that's how it made you feel. …'cause you've got a son you did not know where he was, the doctors were saying 'No, he is fine.' They said he was probably alright. … dreadful, absolutely dreadful. It's not like I was going to do it but I thought about it. ……I am not being melodramatic."

Catherine described being unable to function over that period. She said that she was on her own a lot of the time because she was retired, and her husband was working. She said that she was lying in bed most of the time and had put her life on hold. *"It was like a brick wall ... it was dreadful … it was awful."* The worry and the sadness continued when she found out that Mark was in prison. *"Just worry and ahm, just anxiety and sleeplessness and I just suppose feeling sick, I didn't eat for a good couple of days when I first found out [that Mark was in prison]..."* Seeing her son in court 3-4 years ago before her son was sent to a medium-secure facility added to her sadness: *"To see him, I was in tears all the time. I was very, very emotional. I don't show it sometimes ……. But very emotional, I can't tell you what it's like. It's like being*

in hell. When you've got a child or any relative, I think that has mental health problems, anyway." (Catherine)

Some family members also described experiencing shame about their relative's offending behaviour.

"I don't tell anybody, anybody who needs to know already knows. I don't go out and tell anybody anything really. All my friends and [people who need to] know the situation, I've told them." (Liliane)

Catherine also felt some shame about her relative's aggressiveness. She shared that she did not hide from other's that he has mental health problems and that he has been in prison, but she has not told them about him getting into fights.

Other family members spoke about the guilt they felt about their relative's offending actions: *"I feel like it's my fault, whatever happened to Z* is my fault. I don't know why I feel this way but that's how I feel. …I know I didn't do anything wrong … and I don't know why I think like that….I just feel really guilty … Really." (Liliane)*

Yet other family members described becoming isolated by others due to their relative's mental health difficulties and how this made them even more depressed because it deprived them of the support they needed the most at the moment.

"It made me very depressed because you become isolated when somebody's got a mental health problem … everybody backs off just at the time when you're needing

everybody and they all back off because … it's scary." (Rebecca)

Some family members felt alone and ostracised because of their relative's offending and their friends' reactions to it. Liliane described how she lost an old friend of 30 years when she shared about her relative being in a medium-secure facility. She seemed to have felt betrayed because their children grew up together. The friend made negative comments about her son and Liliane became even more upset and cut contact with her.

"She didn't have anything good to say so I don't talk to her anymore. …She was supposed to be my friend. … She wasn't there for me at the end of the day. …. I keep myself to myself. I don't need no friend." (Liliane)

Family members described how their functioning at work was affected and that they had to take time off work.

"I don't know where I was. I was in a daze, just downhill. I couldn't cope. I had 3 months off work." (Liliane)

"…getting ill I tried work but…." [had to take time off] (Gemma)

Some family members were so unwell that they sought medical help and either considered or were put on medication to help them get through the difficult times.

"If I wanted to, I could've gone to the doctors and gotten antidepressants or whatever but you know …" (Catherine)

"… I used to go to my doctor saying … I'm not feeling great ... they put me on the odd thing now and again but they said to me this will all change when the situation changes. You just got to learn to get through this they said." (Gemma)

"They put me on tablets. My anxiety tablets but I don't really take them very often, very much. … I was getting very down with them so it wasn't something I wanted to be doing." (Liliane)

Other family members sought mental health support to help them cope with the difficult times.

" …. so my anxiety got so bad I had to go and see … some people at Service 1. … For a couple of weeks I used to go to …see this lady … I go to them more or less every year because I get really down at times and I have to go and see them since [son went to a medium-secure facility 4 years ago] … I'm not that bad now." (Liliane)*

Similarly, after learning about her son's abuse, Gemma sought mental health help, *"I mean obviously I had counselling for that, I've been to people, I've put myself into counselling trying to get my head around, you know. And I still got this pent-up anger."*

Some family members also experienced a significant physical impact due to the stress they were under.

"My weight's got up … I have heart problems. ... I've had to have cardiac checks, ECG checks. I've had to have all that done and they said it's like speed up heartbeat ... So it does put a lot of stress on your system. And I can tell you because you are physically feeling it. You physically feel the stress on your system. Especially when Sean was at his worst, you can feel your body really tensing." (Gemma)*

Similarly, Liliane was put on blood pressure tablets because of her son's deterioration and aggressiveness towards his siblings, *"because that Friday night when he started to have a fight with the boys [his brothers] and throwing stuff and I sat here and I cried and I cried and I cried by the time I get to the doctor, I went to the doctor that same evening and my blood pressure was out the window and the man says 'We're gonna have to put you on some tablets' and they put me on the 5ml and then had to up it to 10. So, I've been on tablets since Al took sick [15 years ago] and never came off it."*

Family members experienced negative emotional impacts because of the system as well. Struggling to find appropriate help for their relative took a toll on them.

"…it knocks your will, you can't, you can't function 'cause you are just so worried about different things and like I say that was more to do with NOT GETTING any help … and how it affects you … 'cause once you get someone to listen to you they

get help it relieves, it takes pressure off you but when you are fighting and banging your head off a wall and people are treating, your child you know, with so much disregard it really affects you!" (Gemma)

3.1.1 Sense of threat

An important subtheme that came across in the experiences of all family members was the sense of threat they experienced due to their relative's aggressiveness and propensity for violence, which was turned both towards the family and the general public, and which was unpredictable.

Talking about the aggressiveness towards the family, Rebecca said:

"He attacked everybody in the family, my daughter and my husband … if you'd argued with him, he'd get angry, so you just went along with it. … If he gets up in a bad mood, you'd better watch out, you'd better get out, get away from him and that still happens. That still happens, even when he's been in hospital." (Rebecca)

Similarly, Catherine described her relative's violence towards the family usually when he was very paranoid. *"About 2 years ago there was an incident where he struck his brother, paranoia as this might be…."* Catherine also recalled how traumatic it was for everyone when her son hit his dad 3 years ago and severely injured his eye, which never completely recovered. *"Another time in my life that was absolutely dreadful. … He was very paranoid and he should've been in hospital."* Catherine also admitted to *"A little bit of fear"* when her son gets discharged and if he does not take his medication and having a certain aggressiveness. She was worried about how Mark would react to people and worried about him hitting people and said

that she was selective who she introduced him to from among her friends.

Liliane also echoed a similar fear of her son's aggressiveness when he became very unwell, *"And he mashed up the bed and he mashed up the door. Everything was just mashed up."* She recalled a particular incident a few years ago when her son was getting increasingly violent, so she was afraid to leave him alone in the house with his brothers. *"… one day when it got REALLY bad … was fighting and he made the other brother nearly went out of the window. I'm thinking, 'You can't stay here no more.' I can't, I can't have him in here 'cause I don't want anything to happen to none of them so it was best that he wasn't here no more. Cause I was thinking, I can't go out and leave them in the house … I was sort of afraid in case anything happens while I wasn't here. …. and I saw a different side of him that day so I came home from work and phoned Hospital X*"*

Gemma also described numerous instances when she felt threatened by her son and how this left her feeling on edge and in fear all the time: *"When he was getting unwell he started to be quite threatening, near the end he was getting really seriously threatening towards me. … I would come home from work and if I see Sean's car parked outside at the front … I'd be petrified of going in the house. …Just gets your adrenaline, your adrenaline started you can feel it in your body just going and you're thinking, 'What's he going to be like? Is he gonna be aggressive?'"* Gemma's extreme fear made her vulnerable because she left her doors unlocked, *"…I mean I was living with all my doors open. I wouldn't lock my front door, wouldn't lock my back door. I wouldn't even bolt it where you had to unbolt it to get out. I kept them open where you just pull out the handle. I wouldn't lock up the house….. I*

wasn't bothered about anybody walking in. I was more concerned about what Sean was like in the house." At one point, Gemma had to leave her house, *"…we were staying in hotels 'cause we couldn't stay in the house 'cause we were scared of him."* Later on, when the police removed Sean from the house, Gemma continued to be scared of him, *"… he kept coming to the door then and he was ringing the door, just stood there pressing the doorbell all the time or just stood there staring at the doorbell. It was getting scary … we decided to put protection on our house. Metal bars on the back windows, shutters on the conservatory, film on the glass to stop him breaking the front windows, reinforced front door. It was like a prison because we were scared of Sean getting in and hurting us."*

Family members described their relatives' unpredictable and extreme level of aggression towards non-family members as well. Rebecca recalled an instance when *"We were out walking by the park one day and this couple went past us ... and all of a sudden Bob went for him [the man] 'I heard what you were saying about me'. Grabbed hold of this bloke. … That's how he can go. Just like that. You never know when it's gonna happen or where it's gonna happen."* Due to their relative's past violence and aggression, some family members felt uncomfortable in the presence of their relative and found it difficult to trust him. Anna shared that her family were uneasy with their relative due to his past aggression and that this was something that was at the back of their minds, *"His cousins are not too keen on him because of the things he has done in the past concerning their children. … I don't think there will ever be that trust there again."* Anna's daughter as well keeps her own daughters away from their relative, *"she couldn't relax with her daughters being there and John."*

Peter also emphasised several times that his relative was *"big and strong"*, in addition, he said, *"[The family are] apprehensive about him getting out. He is violent, he was violent if you know what I mean. He is a big lad."*

3.1.2 Worrying about relative's future

All participants expressed numerous worries about the future of their relative. Some family members were quite pessimistic about their relative's future and described it as very bleak, others were more optimistic. Rebecca was one of the former family members.

"Because it's never ending, isn't it. There is no light at the end of the tunnel really. You are always hoping there is but with the way Bob is and all these years. …. I feel so sorry for him. I just but I don't know where it's going to end. … I don't see a future for him I'm afraid. I don't see where he goes from here…."

Some were worried about the potential responsibility they might have towards their relative and the stress this may cause them.

"I don't want him too near me. That might sound a bit …. But I don't want the responsibility of whatever John's doing. ... I just don't want that responsibility. That stress you know. I am here if he needs me. If he gets himself in trouble … then he has only himself to blame. … He can come and have his Sunday lunch here if he is working but I don't want him at my door every day! And I've told him that and he

says, 'Yeah, that's fine'." (Anna)

Catherine had similar anxieties about the *"big responsibility"* she will be faced with once her relative was discharged.

There was also the worry about the reaction of the wider family to their relative when he is released. Peter, for example, feared that the larger family might reject his relative and his relative will not manage it well, will relapse and turn to violence again.

"I just worry that he won't handle the disappointment … of being rejected. John will go and look for family but they might reject him." (Peter)

Anna also worried about the wider family's reactions to their relative and also about what her relative would be like once discharged and in the community considering that he has been in prison for 13-14 years.

"I get a bit anxious if he gets out and wants to go and see the nephews … the reactions what they might … when John starts speaking, the way he used to speak and that caused conflict. So I am a bit wary of them meeting after a drink. I just don't know how his balance would be … how his mental state would be… I don't want him to start being … a nuisance to the family if you like. I don't want him to say I'm going over to [so and so]."

Another worry was related to the relative having a meaningful occupation,

keeping out of trouble and receiving proper support from services.

"He would need something to occupy his days. … If he does something naughty then he'll go for life. He'll never get out. That is the worry. That is the concern we have. He must get proper supervision. Must get that supervision in some form the rest of his life. Because if he stops taking his medication for any reason it is going to be bad." (Peter)

Some of the worries related to the relative's unpredictability and propensity for violence. Peter, for example, expressed a worry about his relative being released because of his past violence. *"Apprehensive about him getting out. He is violent, he was violent if you know what I mean. … And he is a big, strong lad and that is my main concern."*

Catherine also worried about her relative becoming aggressive towards others.

Other family members were anxious and worried about the future because there was no one to look after their relative and they were getting older and were also worried what would happen to him if something was to happen to them.

"It's always there, it's always there (the worry). I don't worry about me at all." (Catherine) "I just want him to stand on his own two feet and just I wanna know that he will be able to look after himself 'cause I'm not around forever … and look after himself and that's my worry now. It's his future. You know, that's my worry! … Is he gonna be okay? You know, if I was to be gone tomorrow how's he gonna be? What's

hum, what he's gonna cope that's more worry now so it doesn't end really, you know." (Gemma)

Yet another worry was the relative's criminal record. *"You know so that's a worry about is that gonna affect him in the future?" (Gemma)*

3.2 Psychological impacts on the wider family

The impact of the relative's difficulties was felt also by the wider family.

"It's been quite horrific for him and for us as a family because the worst he got it reflects on you … It was hell on earth. It wasn't our home anymore. You know, he, he was in control of everything. That's why nobody would take him in when he was on the street because he just takes over. … His brother's been really affected by Bob's illness. Of course, he has. That's why he has anxiety. … It upsets him to see his brother like that." (Rebecca)

Gemma also described how her son's mental illness and his behaviour put so much pressure on the family, that this created friction between Sean's brother and her and they nearly turned on each other.

Liliane also spoke about the psychological impact on her family, *"Even his brother doesn't, one of his brother's says 'Mom, I don't like to go see him in there because it really hurts me to see him in that place.' So he doesn't like to go but he does go to see him. But he doesn't like to."*

Anna spoke of the negative impact on the family because her relative insulted a nephew who had mental health difficulties and said nasty things about his nieces.

"I think they all see him differently. … If he is in dire straits they would help him but they don't want him in the house."

4. Tentative alleviation: The endless process of adapting and accepting

This superordinate theme captures the relief all family members experienced after their relative received appropriate help and with that release of tension and anxiety, both their relative and themselves were able to regain some degree of normality and to resume their lives. The acute stress of seeking help for their relative was over and thus there was an improvement, however, the chronic worry about him remains. Therefore, in contrast to some drama plots there is no full resolution, but an ongoing process of acceptance and adaption to their relative's situation with some family members having moved further along the adapting and accepting cycle than others.

Gemma described how her relative and she herself had resumed their lives. She said about her relative:

"… he got better off 'cause he got the treatment there you know and he is absolutely great now. … He's basically 90-98% there.… We can sit and chat and have a laugh ... It's been so long we've heard him laugh. But now he just laughs at stuff and he laughs at me ... none of that anger's there. He doesn't show any of that. …. That kind of look of coldness. …You know the medication's working really well with him. He still got a bit of the negative side of the condition … but he is still doing stuff so he played rugby again. … He's applied for … engineering apprenticeship which left him to do the induction in the next week which I've found for him."

Gemma also spoke about how she encouraged her relative: *"You are going to be whatever you want to be. …. there are plenty of people … with your condition who were, who are professors, who are doctors whatever. It's what you want to do and if you get on well, you deal with it but otherwise, you just get on with your life."*

Family members spoke how they started to return to 'normality' and to adapt to life after the acute stress they were under. Gemma, for example, has started to resume her life after having lost her job and needing to take a 'lesser' grade job because she did not want too much additional mental pressure. *"I'm back at work again now. I'm in a different job because that job I was in I was made redundant. ... I am a housekeeper in the NHS now. On a ward. I mean tried another areas but work it does affect you in a way that where I could probably be doing more what can I say not intelligent but I was a lab technician and I could do all that but I've gone to housekeeper because I felt with Sean being unwell he needed my support with going to hospital. Didn't want to go into a job where I had to and I know it's terrible but I don't mean that but use my brain too much. You know I do use my brain. Housekeeping is not easy. But I didn't want too much strain on me when I'm trying to help support Sean. So you adjust your life to be there for them ... You know not worrying about a job more responsibility in a job if I had that and I had to I'd rather be where I can just job and be there for Sean." "… I've got a degree, … so this job just pays sufficient for me to do that. And that's it. You do adjust your life to help support ... But I wanna, I need to work so I have to working so I can be there for him."*

Similarly, Catherine felt relieved that her son was getting the help that he

needed and she knew that at the medium-secure unit he was looked after, *"He is here and he is being taken care of…"* Therefore, she said that she felt *"happier and more relaxed"* and she found going to multi-disciplinary team (MDT) meetings helpful. *"It's been a good year for us, knowing that he is safe and that he is progressing"*. Her relative's mental state has also been better than it has been in a few years. *"… you can relax a bit now because you have faith, it has restored my faith in mental health a little bit."* She also felt that she has got her life back, *"I just feel relieved".*

Family members saw a positive difference in their relative when he received appropriate help and this was despite his long-standing mental and offending problems.

"For the last 4 years maybe, I've seen a lot of a difference in him. …I've only known John with mental health issues. I can see from when he was really bad … to now, which he seems normal you know. … You can talk, he listens, not knocking away from you. And he phones me up, you know. He's been over here [to her house]. ... Had a family gathering when he came over. …We keep in touch now. We've got a good rapport with each other now. … and the doctors at Z would phone me up and I'll go over there. … He'll be fine." (Anna)*

"Has been in medium-secure facility 4-5 years. … they've done a great job with him. Absolutely fantastic. He's been so good the treatment he's received there. … He is doing absolutely fantastic. He is more focused." … I'm looking forward to seeing him. I want him out. Human beings shouldn't be locked up. I never thought he would

get well enough to come out. I never thought he would get out." (Peter)

Some family members were happy that their relative was receiving appropriate care and despite the alleviation, they were somewhat pessimistic about the long-term outlook for their relative because of his long-standing mental health and offending problems.

"It's upsetting [son being in a medium-secure facility] because that's my son. But as I said you can't have him to live with you either. … He's a nightmare to live with. ...You know I hate to see him like this now but at least when I say to people I'm really upset that where he is but at least he's got shelter and he's got food before he was on the street but that's not what you want for one of your children, is it? … Because it's never ending, isn't it? There is no light at the end of the tunnel really. You are always hoping there is but with the way Bob is and all these years." (Rebecca)

Some family members were still at the beginning of the adapting and accepting process and although they have noticed an improvement in their relative's mental state, they were still coming to terms with his offence and him being in a medium-secure facility:

"He's alright in there though. He's happy. … We sit down and we chat. He's a lovely boy. He's decent. We are alright together. … I love my son, I love my son. …. and I miss that he is not out here doing his own thing instead he's locked away. … I want Al to come out and pick up his life. Make something of his life. … He's got his whole

life ahead of him. … I want to be here for the day he comes out and … I want to be here for him…. Even now if anybody says where is your son, I haven't seen him for a while? Because not everybody knew about the situation. Even last year the neighbours who lived down the road asked me about him and … the tears started and she said I am sorry I didn't know so …." (Liliane)

Discussion

The aim of the present research was to examine the psychological impact on family members of men detained in a medium-secure facility due to offending and mental health problems.

A drama plot was used as a metaphor to describe and interpret participants' experiences and to organise the four superordinate themes. The prelude theme provided the context to the difficulties family members experienced. It captured family members trying to make sense of their relative's transformation and deterioration. They noticed a sinister change in their relative, which they experienced as the loss of someone they knew and the emerging of a stranger. This deterioration was gradual and progressive spanning between 4 and 20 years, with frequent stays in mental health institutions and prison. Family members struggled to understand how it was possible for their relative's state to deteriorate so much as to warrant a detention in a medium-secure facility. They tried to make sense of their relative's deterioration by attributing it to a mental health illness such as schizophrenia, to substance abuse, adverse childhood experiences (abuse, neglect, parental mental illness), destiny, bad luck or a test of the family member's strength. They tried to support their relative by seeking professional help for him, and by providing emotional and material support but despite their efforts, they felt powerless to stop their relative's deterioration because they kept being directed from service to service. Understanding family members' needs and supporting them is vital because they often continue to support and care for their relative well into adulthood (Ridley et al., 2010). In addition, as discussed in the introduction, studies have shown that good family ties reduce re-offending due to the emotional and

practical support provided by family members (Datchi, Barretti, & Thompson, 2016; May, Sharma, & Stewart, 2008; Niven & Stewart, 2005).

In the build-up theme, participants described feeling let down by the system. Family members described the anger, frustration and exhaustion the struggle to find help for their relative caused them and the hurt they felt for not being listened to and involved in the care and decisions for their relative's well-being. Family members' lack of support and them not being allowed to contribute to the care of their relative has been documented previously (Gray et al., 2010; McCann et al., 1996). The journey to obtaining appropriate help spanned between 4 and 25 years. Families felt that the system failed them by not recognising the seriousness of their relative's condition and by not offering appropriate and timely help which led to their relative's problems escalating, including being charged with a crime and detained in a medium-secure unit, which gave relatives the added burden of having a criminal record, in addition to their serious and long-standing mental health problems. Families felt victimised by the system because their relative was caught in a revolving door between prison, hospital, the street, and home without really receiving the needed or appropriate help.

The culmination theme captured the height of the family members' stress and distress. The family members' feelings of powerlessness, frustration, anger, being ignored by the system and the mental and practical resources it took to support their relative led to significant psychological impacts such as anxiety, depression, suicidal thoughts, and physical health problems (heart problems and hypertension). It also led to feelings of guilt and shame, and isolation which increased the family members' psychological burden. Their relative's aggression and their worry about

his future contributed to this negative psychological impact, which was also felt by the wider family. Ferriter and Huband (2003) described similar impacts on parents of patients diagnosed with schizophrenia. They found that the most common reactions of parents were stress, loss and fear. They also reported that violence, withdrawal and verbal aggression were the most challenging behaviours for parents. As discussed in the introduction, governments have acknowledged the importance of supporting family members and organisations have been created to do so, however, more programmes appear to be needed as well as programmes adapted to the specific needs of particular family member populations such as those of family members who deal with the double problematic of having a relative with mental health and offending problems.

The alleviation theme captured the ongoing process of continuous acceptance and adaptation. The relative had improved with the appropriate help and the acute stress the family member was under has dissipated and things had returned to some normality. Family members resumed their lives, however, their worry about their relative relapsing, not seeing a future for him or not having come to terms with the crime he has committed felt like accepting and adapting was an endless process.

The current study found similar themes to two other studies which have examined the impact on the family member.

Sturges and Hanrahan (2011) interviewed 27 mothers of offenders about their experiences of having a son who was imprisoned. They found seven themes: initial reactions and responses, blame, stigma, relationship dynamics, criminal justice responses, stress, coping and acceptance. The authors reported that

mothers experienced the criminal justice system as unhelpful towards their sons and themselves and as stigmatising. Two-thirds of the women reported a lot of stress which was experienced as physical (hypertension, heart problems, weight loss) and psychological problems such as distress, depression, worry, and in some instances feeling suicidal. Some took psychotropic medication to help them cope. In addition, powerlessness was a common theme. Other themes included guilt, shame, and isolation due to the stigma of their son having committed a crime. Mothers felt that the offence was not an event but a continuous process of adaptation and adjustment, lasting years and pervading every aspect of their life, effectively a 'life sentence'. We can see that the themes in the current study overlap with the themes found by Sturges and Hanrahan despite that the authors focused only on mothers of offenders.

A recent study by Finlay-Carruthers, Davies, Ferguson, and Browne (2018), which was consulted only after the analysis and the write-up of the current paper, validated the findings of the present research. The authors interviewed three mothers and three fathers of four male and two female patients with a functional diagnosis of psychosis who were currently detained in a regional adult medium-secure forensic unit in the United Kingdom. Three superordinate themes emerged from their IPA analysis, the content of which was very similar to the one in the present research. The first theme, 'Something's not right'- the onset of mental distress, described family members realizing that something was wrong with their relative who became aggressive, abusive and violent. Family members tried to make sense of this change in behaviour and personality but could not and felt anxious, powerless, and vulnerable. However, they persisted in caring for their

relative and attempted to manage increasing difficulties sometimes resorting to calling the police. This theme is very similar to the prelude and build-up themes in the current study.

In the second theme, ‘It’s a terrible battle’- relating with professionals, family members described the stressful process of seeking help for their relative. They struggled with services who would not hear and acknowledge their concerns, and this increased the strain on them, leaving them feeling angry, disempowered, helpless and hopeless. Family members deplored the lack of communication from services and wanted to be more involved in the care of their relative. They felt that had they not been ignored, their relative would not have deteriorated and detention in a forensic mental health service could have been avoided. Upon admission in a medium-secure unit, family members experienced a relief and recuperation of their emotional and physical strength. This theme is similar to the culmination theme in the present paper.

The third theme, ‘A very sad fact of life’- caring with no end in sight, described how family members struggled with the diagnosis of their relative although this could explain the negative transformation in him/her. They also struggled with feelings of responsibility and worried about the permanence of caregiving. Due to the unpredictability of their relative’s illness family members were also concerned about their future and oscillated between hope and fear due to the uncertainty of their relative’s mental state. This theme bears similarities to the alleviation theme in the present research.

As the above summary illustrates, the current findings are in concordance with those of Finlay-Carruthers et al. (2018) although their participants included

fathers as well as mothers and their relatives were both women and men.

A suitable model that may help to understand and to provide theoretical basis for interpretation of the experiences of family members is the stress and coping model proposed by Lazarus (1991) and illustrated below (Figure 2.2). The transactional stress and coping model states that a transaction occurs between a person and the environment and stress results from an imbalance between demands and resources. We become stressed when demands exceed our resources. All family members in the current study experienced high levels of stress in relation to having a relative with mental and offending problems and an unhelpful system and felt overwhelmed.

The interpretation of a stressful event depends on the individual's appraisal of this event, that is, their interpretation of the significance of the event. Lazarus (1993) postulated two appraisals, primary and secondary. Primary appraisal involves interpreting the stressor (harm, threat, challenge) and secondary appraisal is concerned with analysing the person's available resources and options. In the present research, family members appraised the situation they were in as threatening for their relative's well-being and afterwards for their own well-being as well. Once they recognised that there was a problem, they appraised what the options were. They could draw on internal resources such as their will to help their relative and on external resources such as the support of their social network and professionals.

The theory also postulates that people's appraisal of a situation is moderated by personal and situational factors. Personal factors are motivations, goals, values and expectancies and situational factors are "predictability, controllability, and

imminence of a potentially stressful event" (p. 15165, Krohne, 2001). In the present study, family members were motivated to help their relative, which seemed in line with their values that you should help your family and/or people who are in distress and in need of help, however, the deterioration of their relative was imminent, their internal resources were overwhelmed and the external resources were insufficient or unavailable.

Coping follows the appraisal of the situation. Lazarus (1991) suggested two broad types of coping. Problem-focused coping attempts to manage or alter the situation and emotion-focused coping aims to regulate the emotional response, that is, to change the relation to the situation. Family members within this study displayed both types. They tried to manage the situation by seeking professional help for their relative and by supporting their relative emotionally and materially, however, this was not sustainable for most family members. Since family members could not change the situation, they adapted to it by accepting it and by seeking professional help for the distress they were experiencing themselves.

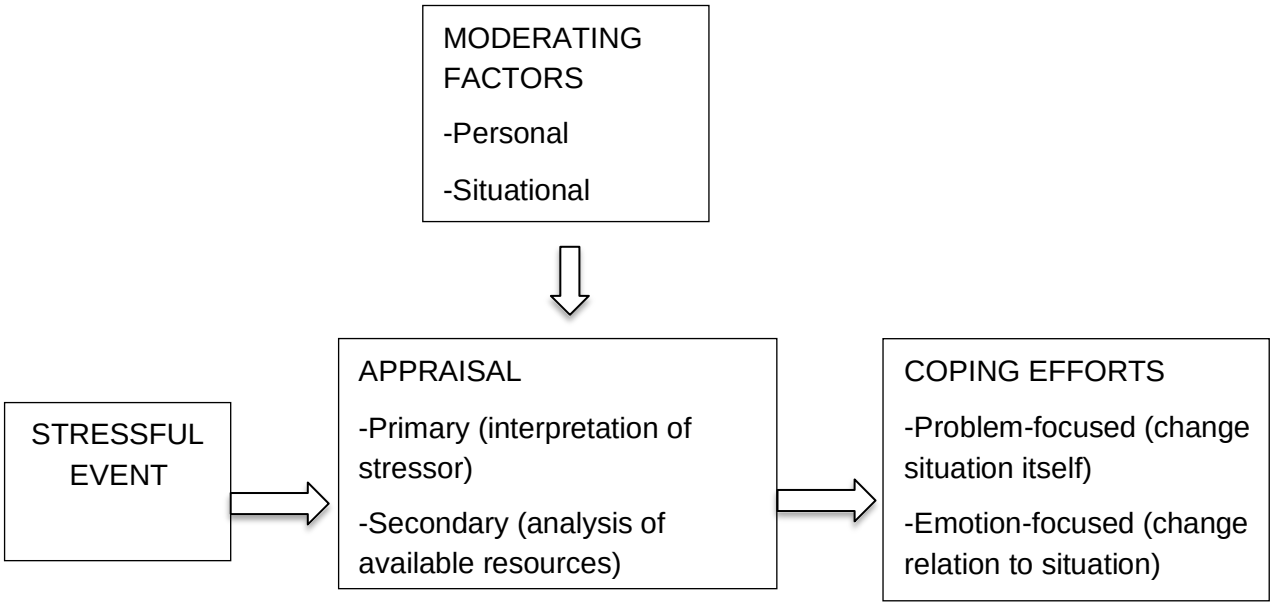

Figure 2.2. Transactional Model of Stress and Coping (Lazarus, 1991).

Limitations

Recruiting participants who opted-in to be contacted may have excluded participants who were less motivated or less involved in their relative's care, however, within the constraints of this study recruitment of a less engaged group was not practical due to confidentiality and ethics committee requirements.

A lack of ethnic diversity in the present study is another limitation. Five out of the six participants interviewed were White British. However, it is well-documented that ethnic minorities are over-represented in forensic settings (Saltus et al., 2013). Minorities may have different experiences and this needs to be researched further and addressed in future studies.

Although acceptable for doctorate-level research (Smith, Flowers, & Larkin, 2009), the number of participants in the present study could be seen as relatively low and this is compounded by the participation of two related members of the

same relative. Whilst this may be considered to influence the findings, it can also be argued that the focus of the research question is on the family member's own experience, which may be different for the two individual family members even if related and facing the same challenges arising from the same relative. A larger sample for the purposes of IPA analysis would have been desirable, however, there were a number of challenges that were beyond the researcher's (IL) control. There was a delay in obtaining ethics approval because the ethics committee argued for the need of double consent (i.e., requesting consent from the relative with offending history initially prior to approaching their family member for their own consent). Analysing the available psychological literature on different carer populations and demonstrating that double consent was an extremely rare exception helped to finally obtain approval but this process (that involved submitting arguments and evidence to the committee on two separate occasions) resulted in a lengthy delay. In addition, there were difficulties with recruitment due to the sensitive nature of the study, the stigma attached to having a relative in a medium-secure facility and the short period of time left for recruitment due to the delay in obtaining ethics approval already mentioned and the need to start the analysis and the write-up for the thesis.

Clinical implications

There are several implications for people with serious mental health and offending behaviours and their family members. People with serious mental health difficulties do not seem to access appropriate services quickly enough and this leads to an escalation of their difficulties such that they frequently find themselves in contact with the legal system. Once in prison, they do not receive appropriate help and their mental health deteriorates further. This not only leads to a loss of potential

and a lack of meaningful life and occupation for the person, but it also places a burden on family members and is a loss to society. Mental health services should be more proactive and should intervene earlier in order to prevent this escalation and minimise the human and economic costs. Family therapies, for example, have proven successful in preventing reoffending, improving offenders' mental health and improving family relations (Datchi & Sexton, 2013).

There is also what appears to be a significant yet not fully acknowledged psychological impact on family members' mental and physical well-being. One way in which we can conceptualise this impact involves using the transactional model of stress and coping originally proposed by Lazarus (1991). When faced with the chronic stress of a relative with mental health and offending problems, family members draw on their internal resources to help and support their relative. These internal resources include their will, desire, ability, and capacity to offer moral and material help and support to their relative while also having to cope with the demands of their personal, professional, and social lives. However, these resources are finite and with time family members may become overwhelmed and exhaust their resources. According to the model, there are two avenues to help and support family members. One possibility is to offer appropriate services and help to their relative, which would offer family members some respite and would allow them to recuperate and to replenish their internal resources. A second option would be to offer help and support to family members themselves in their own right and this could be through professional services such as counselling or psychotherapy or through peer support groups. Carers' programmes can have the added benefit of breaking the isolation family members experience by providing a safe and non-

stigmatising environment where family members can share experiences and support each other (Greenwood et al., 2013).

Adjustments in the environment surrounding family members and their relatives could also be envisioned. Since the police are frequently involved in the process of the relative receiving help, they could receive training on signposting families to appropriate services or organisations. Once the relative enters the mental health system, family members could also be included in the care of their relatives such as being invited to multi-disciplinary meetings and care reviews thus keeping them involved in their relative's care. Furthermore, this would build on current evidence already discussed in the introduction (Datchi, Barretti, & Thompson, 2016; Datchi & Sexton, 2013; May, Sharma, & Stewart, 2008; Niven & Stewart, 2005) that the index offenders and people with mental health difficulties whose families are involved in their care tend to have better outcomes.

Future directions

More research focused on the psychological impacts and needs of family members of men detained for offending and mental health problems is required because this is a neglected topic to date. In addition, more ethnically varied samples are needed. The experiences of other family members should also be further researched considering the significant impact felt by the wider family in the present study.

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CHAPTER THREE – PUBLIC DISSEMINATION DOCUMENT

PSYCHOLOGICAL IMPACTS FOR FAMILY MEMBERS CARING FOR PEOPLE WITH MENTAL HEALTH AND ALCOHOL PROBLEMS

Supervised by: Prof Alex Copello

Public Dissemination Document

This document summarises two research components including (1) a systematic review paper and (2) an empirical study, submitted in partial fulfilment for the Clinical Psychology Doctorate at The University of Birmingham.

Psychological impacts for family members caring for people with mental health and alcohol problems

The research described below was an attempt to investigate and to understand the psychological experiences of two groups of people, one affected by heavy alcohol consumption, and the second affected by their relative's mental health and offending behaviour problems. Each part is described in more detail below

Systematic review paper: What is the prevalence and nature of the psychological impacts of heavy drinking on the social network of heavy drinkers?

The review study background: Three million deaths worldwide are attributable to the harmful use of alcohol every year. Excessive drinking affects both the physical and psychological well- being of the problem drinker and of people around them. Some of the well-documented negative consequences for partners of heavy drinkers are intimate partner violence, marital problems, poor quality of life, and stress. Studies have also suggested psychological effects on family members,

however, the majority of these were small sample studies of partners with pre-selected populations.

The aim and methods used: The present systematic review aimed to examine (1) the prevalence of harmful alcohol consumption in the general population and (2) the nature of the psychological effects on the social network of heavy drinkers. It examined papers of general population surveys with large, randomly selected samples. A systematic literature search of published quantitative studies in three databases was conducted and nine relevant papers were identified and reviewed.

The results: The general prevalence of harms experienced from others' problem drinking in the studies reviewed, ranged between 28.8% and 34.9%. Problematic alcohol use led to depression and anxiety in the social network of heavy drinkers. The severity of the impact increased with the closeness of the relationship. However, some studies suggested that the impact may not be direct but may be mediated by the negative consequences caused by the heavy alcohol consumption.

The conclusions: The present findings highlight the need for more research on the impacts of heavy drinkers on their social network while ensuring that other potential causes are considered and taken into account; that clear definitions of 'problem drinking' and 'negative impact' are used; and that broader influences, going beyond depression and anxiety are considered.

Empirical Study: A qualitative study of the psychological impact on family members of men admitted to medium secure facilities due to offending behaviour and mental health difficulties

The review study background: Studies and recent government initiatives have recognised the important role family members play in supporting relatives who have mental health difficulties and relatives who have offended. However, research on the impacts on family members of people with both mental health and offending problems is lacking. Previous research on offending and on mental health, suggests that family members may experience stigma, isolation, psychological, relational and social burdens.

The aim and methods used: The aim of the study was to examine the family members' experiences of having a male relative with both mental health and offending problems who was detained in a medium-secure facility. Interviews were conducted with six family members. These were transcribed and analysed with a qualitative technique called Interpretative Phenomenological Analysis (IPA).

The results: A drama plot was used as a metaphor to describe and interpret participants' experiences and to organise them in four themes:

(1) Prelude which provided the context to the difficulties family members experienced. It described how they noticed a deterioration in their relative and tried to make sense of it by attributing it to various causes such as mental illness, substance abuse or negative childhood experiences. Family members tried to cope

with this deterioration by seeking professional help which was difficult to obtain and that left them feeling powerless.

(2) Build-up which captured the journey of the family members and their relative through the system. Family members felt let down by the system because finding appropriate help for their relative was a struggle which spanned from 4 to 25 years. Being directed from service to service left family members angry and frustrated and feeling that they have been victimised by the system.

(3) Culmination which captured the negative impacts on family members and the wider family. These were experienced as anxiety, depression, guilt, shame, isolation, and physical health problems.

(4) Tentative alleviation which described the adaptation and acceptance process of family members. Despite the improvement in their relative and the resumption of some normality, family members felt that this was an endless process.

The conclusions: The impact on family members of male relatives with mental health and offending problems who are detained in medium-secure facilities is significant and needs to be addressed by government policy and mental health services which will help to alleviate their burden.

More information can be obtained from Iliana Lilova using the contact information below:

Address: The University of Birmingham
School of Psychology
Vincent Drive Edgbaston
B15 2TT

Email: [redacted]

Appendices

Appendix One: Adjacent Search Terms Used

((family adj2 depress*) or (family adj2 anxiety) or (family adj2 anxious) or (family adj2 stress*) or (family adj2 distress) or (family adj2 mental*) or (family adj2 negative) or (family adj2 emotion*) or (family adj2 affective) or (family adj2 morbidity) or (family adj2 burden) or (family adj2 wellbeing) or (family adj2 "life satisfaction") or (families adj2 depress*) or (families adj2 anxiety) or (families adj2 anxious) or (families adj2 stress*) or (families adj2 distress) or (families adj2 mental*) or (families adj2 negative) or (families adj2 emotion*) or (families adj2 affective) or (families adj2 morbidity) or (families adj2 burden) or (families adj2 wellbeing) or (families adj2 "life satisfaction")).tw.

OR

((relative adj2 depress*) or (relative adj2 anxiety) or (relative adj2 anxious) or (relative adj2 stress*) or (relative adj2 distress) or (relative adj2 mental*) or (relative adj2 negative) or (relative adj2 emotion*) or (relative adj2 affective) or (relative adj2 morbidity) or (relative adj2 burden) or (relative adj2 wellbeing) or (relative adj2 "life satisfaction") or (relatives adj2 depress*) or (relatives adj2 anxiety) or (relatives adj2 anxious) or (relatives adj2 stress*) or (relatives adj2 distress) or (relatives adj2 mental*) or (relatives adj2 negative) or (relatives adj2 emotion*) or (relatives adj2 affective) or (relatives adj2 morbidity) or (relatives adj2 burden) or (relatives adj2 wellbeing) or (relatives adj2 "life satisfaction")).tw.

OR

((partner* adj2 depress*) or (partner* adj2 anxiety) or (partner* adj2 anxious) or (partner* adj2 stress*) or (partner* adj2 distress) or (partner* adj2 mental*) or (partner* adj2 negative) or (partner* adj2 emotion*) or (partner* adj2 affective) or (partner* adj2 morbidity) or (partner* adj2 burden) or (partner* adj2 wellbeing) or (partner* adj2 "life satisfaction") or (couple* adj2 depress*) or (couple* adj2 anxiety) or (couple* adj2 anxious) or (couple* adj2 stress*) or (couple* adj2 distress) or (couple* adj2 mental*) or (couple* adj2 negative) or (couple* adj2 emotion*) or (couple* adj2 affective) or (couple* adj2 morbidity) or (couple* adj2 burden) or (couple* adj2 wellbeing) or (couple* adj2 "life satisfaction")).tw.

OR

((husband* adj2 depress*) or (husband* adj2 anxiety) or (husband* adj2 anxious) or (husband* adj2 stress*) or (husband* adj2 distress) or (husband* adj2 mental*) or (husband* adj2 negative) or (husband* adj2 emotion*) or (husband* adj2 affective) or (husband* adj2 morbidity) or (husband* adj2 burden) or (husband* adj2 wellbeing) or (husband* adj2 "life satisfaction") or (wife adj2 depress*) or (wife adj2 anxiety) or (wife adj2 anxious) or (wife adj2 stress*) or (wife adj2 distress) or (wife adj2 mental*) or (wife adj2 negative) or (wife adj2 emotion*) or (wife adj2 affective) or (wife adj2 morbidity) or (wife adj2 burden) or (wife adj2 wellbeing) or (wife adj2 "life satisfaction")).tw.

OR

((wives adj2 depress*) or (wives adj2 anxiety) or (wives adj2 anxious) or (wives adj2 stress*) or (wives adj2 distress) or (wives adj2 mental*) or (wives adj2 negative) or (wives adj2 emotion*) or (wives adj2 affective) or (wives adj2 morbidity) or (wives adj2 burden) or (wives adj2 wellbeing) or (wives adj2 "life satisfaction") or (spouse adj2 depress*) or (spouse adj2 anxiety) or (spouse adj2 anxious) or (spouse adj2 stress*) or (spouse adj2 distress) or (spouse adj2 mental*) or (spouse adj2 negative) or (spouse adj2 emotion*) or (spouse adj2 affective) or (spouse adj2 morbidity) or (spouse adj2 burden) or (spouse adj2 wellbeing) or (spouse adj2 "life satisfaction")).tw.

OR

((carer* adj2 depress*) or (carer* adj2 anxiety) or (carer* adj2 anxious) or (carer* adj2 stress*) or (carer* adj2 distress) or (carer* adj2 mental*) or (carer* adj2 negative) or (carer* adj2 emotion*) or (carer* adj2 affective) or (carer* adj2 morbidity) or (carer* adj2 burden) or (carer* adj2 wellbeing) or (carer* adj2 "life satisfaction") or (caregiver* adj2 depress*) or (caregiver* adj2 anxiety) or (caregiver* adj2 anxious) or (caregiver* adj2 stress*) or (caregiver* adj2 distress) or (caregiver* adj2 mental*) or (caregiver* adj2 negative) or (caregiver* adj2 emotion*) or (caregiver* adj2 affective) or (caregiver* adj2 morbidity) or (caregiver* adj2 burden) or (caregiver* adj2 wellbeing) or (caregiver* adj2 "life satisfaction")).tw.

OR

((parent adj2 depress*) or (parent adj2 anxiety) or (parent adj2 anxious) or (parent

adj2 stress*) or (parent adj2 distress) or (parent adj2 mental*) or (parent adj2 negative) or (parent adj2 emotion*) or (parent adj2 affective) or (parent adj2 morbidity) or (parent adj2 burden) or (parent adj2 wellbeing) or (parent adj2 "life satisfaction") or (parents adj2 depress*) or (parents adj2 anxiety) or (parents adj2 anxious) or (parents adj2 stress*) or (parents adj2 distress) or (parents adj2 mental*) or (parents adj2 negative) or (parents adj2 emotion*) or (parents adj2 affective) or (parents adj2 morbidity) or (parents adj2 burden) or (parents adj2 wellbeing) or (parents adj2 "life satisfaction")).tw.

OR

(("significant other" adj2 depress*) or ("significant other" adj2 anxiety) or ("significant other" adj2 anxious) or ("significant other" adj2 stress*) or ("significant other" adj2 distress) or ("significant other" adj2 mental*) or ("significant other" adj2 negative) or ("significant other" adj2 emotion*) or ("significant other" adj2 affective) or ("significant other" adj2 morbidity) or ("significant other" adj2 burden) or ("significant other" adj2 wellbeing) or ("significant other" adj2 "life satisfaction")).tw.

Appendix Two: Participant Information Sheet

Title of Project: **A qualitative study of the psychological impact on family members of men admitted to medium secure facilities due to offending and mental health difficulties**

Researcher: Iliana Lilova

Thank you for expressing interest in this research study.

My name is Iliana Lilova and I am a Trainee Clinical Psychologist at the University of Birmingham. I am carrying out this research as part of my doctoral qualification in Clinical Psychology. My interest stems from my previous work in a forensic setting with detainees experiencing mental health problems and the impact imprisonment can have on their family members.

Before you decide whether you would like to participate, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully, it may address any questions you may have. Feel free to discuss with others if you wish.

What is the purpose of this study?
There is little understanding of the psychological impact on the wellbeing and health of family members who have a relative with mental health problems detained in a medium secure facility. This is surprising given the significant number of detainees who experience mental health problems.

The purpose of this study is to conduct interviews to gain a detailed understanding of family members' experiences of caring for a relative admitted to a medium secure facility as a result of offending and related mental health problems. We are interested in identifying some of the challenges you may have faced or continue to face, sources of support that were or could have been helpful at the time and to gain an understanding of your relationship with your relative and how his actions affected you and the relationship you have. Your experiences may improve our understanding of the impact the detainee had on you as the main caregiver, the challenges you face, and access and barriers to support services. This information may help to understand how people cope with and recover from difficult life events, improve medical and administrative professionals' knowledge of needs amongst relatives of offenders, and improve the provision and accessibility to services for relatives.

Why have I been invited to take part?
You have been invited to take part in the study because you have a relative admitted to a medium secure facility as a result of offending and related mental health problems. In total, we are hoping to recruit between 6 and 10 participants to take part in the study.

Do I have to take part?
No, participation in the study is completely voluntary. It is up to you to decide whether or not you want to take part in it. If you do, the researcher will go through this information sheet with you and answer any further questions you may have. You will be provided with a copy of the information sheet and asked to sign a consent form showing that you have agreed to participate. You are still free to withdraw from the study at any time before the interview. If you decide to withdraw during or after the interview is completed, you have up to one month to withdraw your data (the interview transcript), after which data analysis will begin. You do not need to provide a reason if you decide not to participate or if you withdraw at any time. Furthermore, there will be no repercussions should you decide not to take part or to withdraw.

What will happen to me if I agree to take part?
If you decide to participate, you will be invited to take part in either one or two shorter interviews (depending on your preference) to talk about your experiences and the impact of having a relative admitted to a medium secure facility as a result of offending and related mental health problems. In total, the interview(s) is/are expected to last approximately one hour although it is possible that interviews could last longer if regular breaks are required, and this could extend to a maximum of two and a half hours if necessary.

You will also be asked to complete two brief demographic questionnaires. This data will help us to compare our results to results from other studies. However, completing the demographic questionnaires is optional.

You will be asked to either contact the researcher directly, whose information is provided at the end of the sheet, or to leave your details with your contact at the National Health Service Foundation Trust (NHS), so the researcher can contact you directly, to arrange the best date, time and place to carry out the interview. The interview can be held in one of the medium secure facilities at NHS or in a booked venue such as a General Practitioner's surgery, close to your home. The researcher will then meet with you at your preferred location and time. The interview is likely to last anywhere between one to one and a half hours although this will be flexible depending on whether you would prefer one or two shorter interviews. You do not need to indicate a preference for one or the other prior to the interview; this can be decided once the interview has started. The interview will involve an open discussion about your experiences following the detention of your relative. You will have the opportunity to see the interview questions before the interview and let the researcher know if you have any concerns. There are no right or wrong answers to the questions, the main aim is to get an understanding of your experience. I understand that this is an emotional topic therefore if needed you will have the opportunity to take breaks during the interview. With your consent, the interview will be recorded on a voice recorder, so that the discussion can be analysed in greater detail without the researcher forgetting important details. You can request for the recording to be stopped at any time during the interview. The recording will be coded with a unique identification number and any identifiable information such as

names and places will be pseudo-anonymised in the transcript in order to prevent the possibility of you being recognised.

Is the interview confidential?
Everything you say during the interview is confidential except if you disclose information indicating that either you or someone else is at serious risk of harm or if you report a criminal activity not previously known. This will be discussed with my academic supervisor and University guidelines will be followed, however, I will talk to you about my concerns before raising the issue with my supervisor.

What will happen after the interview?
After the interview, the researcher will type out the discussion from the interview, word for word. You will be sent a copy of the transcript to review within the one month reflection period after the interview, to ensure that you are happy with the content as direct quotes are likely to be used from your transcript to describe particular experiences when writing up the final report for the study. You will have the opportunity to discuss any concerns with the researcher in person or over the telephone.

What will happen if I do not want to carry on with the study?
If you agreed to participate in the study and then changed your mind before the interview has taken place, any data collected from you will be kept for 10 years. If you wish to withdraw during the interview, or once the interview has been completed, you have a period of one month to withdraw your data, after which data analysis will begin. You do not need to provide a reason if you decide not to continue with the study and there will be no repercussions.

What will happen to my personal information?
The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Birmingham will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained for 10 years. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at https://www.birmingham.ac.uk/schools/psychology/centres/cap/index.aspx.

The University of Birmingham will collect information from you for this research study in accordance with our instructions.

The University of Birmingham will keep your name and contact details confidential

and will not pass this information to anybody else. The University of Birmingham will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from The University of Birmingham and regulatory organisations may look at your research records to check the accuracy of the research study. They will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

What will happen to the data collected in the study?
After the interview, the recording will be transcribed on a password protected computer at The University of Birmingham by Iliana Lilova and allocated a unique identification number that will be used to identify all information related to you, so only the researcher will be able to recognise you. Once transcribed and saved onto a password protected University of Birmingham computer, the recording will be deleted off the voice recorder. All other information collected (including demographic information and transcripts) will also be assigned the same unique identification number and be stored in locked filing cabinets at The University of Birmingham. Consent forms will be stored in a separate filing cabinet, as you will be asked to provide your contact details if you would like to see a copy of your interview transcript in the one month reflection period or receive a copy of the findings once the study has finished. In line with the University's code of practice for research data, all data collected for the study will be preserved and accessible for ten years by the research team and the university data steward who is responsible for archiving the data. After 10 years the data will be destroyed. The research team and the data steward are trained to manage this information in accordance with university, national and local guidelines on confidentiality and data protection. Direct quotes from the interviews are likely to be used in final reports; however, this will not include any participant identifiable information. You will have the opportunity to read your interview transcript before any quotes are used in reports, to ensure you are happy with the interview content.

What are the possible disadvantages and risks of participating in this study?
It is possible, given the sensitive nature of the topics to be discussed during the interview that you may feel upset. A number of steps will be taken to minimise any distress you may experience, including the opportunity to see the interview questions before the interview takes place. Furthermore, if you feel yourself getting upset during the interview, please let the researcher know and you will be able to take as many breaks as you need, or if more suitable, you can stop the interview to be continued at a later time. At the end of the interview, you will be debriefed by the researcher and if required information on support services could be provided.

Are there benefits from participating in the study?
There are no direct benefits from participating however, some people find it helpful to talk and reflect on their experiences. Furthermore, your experiences may be helpful in providing us with a better understanding of family members' experience of having a close relative detained in a secure hospital as a result of offending and

related mental health problems. This will help us to understand some of the challenges you faced (or continue to face), sources of support that would be helpful, improve knowledge of coping with and recovering from a difficult life event, and improve knowledge of needs amongst professionals and access to support services.

Will my travel costs be reimbursed?
Your travel costs will not be reimbursed, however, to minimise your travel, interviews will be held at BSMHFT's site when you visit your family member or in a booked venue close to your home.

What happens when the research study stops?
At the end of the study, we will describe the findings in a report, which we hope to publish. You will be asked to indicate when you consent to participate in the study whether you would like to receive a copy of the research findings. If you wish to do so, a copy of the report will be sent to you.

Who has insured and who is sponsoring the study?
The study is insured and sponsored by the University of Birmingham.

What if there is a problem?
If you have concerns about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (contact details are provided at the end of the sheet). If you are unsatisfied with the answers provided or have any cause to complain about any aspect of the way in which you have been approached or treated during the course of the study, you may contact the supervisor of the Clinical Psychology trainee, Prof Alexandre Copello, at .

If you wish to speak to a person independent from the study, you can contact Dr Sean Jennings who is the Research Governance and Ethics Manager at The University of Birmingham. His contact details are:

Address: Research Support Group
University of Birmingham
Edgbaston, Birmingham
B15 2TT

Telephone:
E-mail: researchgovernance@contacts.bham.ac.uk

You could also contact the Patient Advice and Liaison Service (PALS) which offers confidential advice and support to patients and their relatives or carers. You can find the nearest PALS office by calling NHS 111 or on their website: https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363

If you would like to discuss any aspect of this research, please contact Iliana Lilova

Tel:

Email:

Post: School of Psychology
University of Birmingham Edgbaston
Birmingham B15 2TT

(21-09-2018, version 4)

Appendix Three: Interview schedule

The schedule is divided into five main sections. Each section will start with a broad question and this will be followed by prompts as required. The sections include: the relationship between the family member and his relative; the impact of having a relative detained in a medium secure facility; the psychological impact on the caregiver; the caregiver's attempts to cope and adapt; support received/ not received, and the future as seen by the family member.

A. RELATIVE, SOCIAL ENVIRONMENT AND RELATIONSHIP WITH RELATIVE

Purpose: To get to know the relative, the social environment and the relationship of the main caregiver with his relative before and after the relative was detained in a medium secure facility.

I. Could you please describe your relationship with your relative [*the name of the person will be used here and thereafter]* before and after he was detained?

1) Did your relative live with you prior to being detained?
   Possible prompts: *If not, how frequently were you in contact with him? Where did you live? What was the neighbourhood like (poor, well-to-do, any risks/problems)?*
2) Could you please tell me a little bit about your family?
   Possible prompts: *Immigration history? Languages? Religion and observance of customs/ traditions? Any changes that have happened prior to the offence?*
3) How is your relationship with your relative?
   Possible prompts: *Did this change over time? Has your relative's mental health problem affected your relationship with him? Have his actions, trial and subsequent hospital admission affected your relationship with him?*

B. THE IMPACT OF HAVING A RELATIVE IN A SECURE FACILITY

Purpose: To understand the circumstances surrounding the relative's actions and the main caregiver's reactions to these.

II. Could you please tell me about your relative's actions and your thoughts and reactions to them?

1) Did you see the action yourself, or did you hear about it later?
2) Could you please tell me about your thoughts in response to your relative's actions? What sense, if any, did you make of what happened?
   Possible prompts: *What went through your mind? What were your thoughts? Was this influenced by the nature of your relative's actions? Has this changed over time? What sense, if any, do you make of what happened now?*

3) What was your experience of the entire process (trial, conviction, admission to a secure facility, visitation)?
Possible prompts: *What was it like interacting with various professionals and government agencies?*

C. CAREGIVER'S HEALTH AND WELL-BEING

Purpose: To gauge the psychological impact on the main caregiver of his relative's actions and mental health problems.

III. Could you please tell me how what your relative did affected you personally?

1) Could you please tell me about any changes you experienced to your physical and psychological health in the months following your relative's actions?
Possible prompts: *Can you describe what felt different, what felt the same? Has this changed over time? Have any pre-existing problems been exacerbated?*
Check possible physical symptoms: migraines, weight loss/gain, fatigue, hypertension, heart condition, IBS, muscle aches & tension.
Check possible psychological symptoms: mood (sad, anxious, irritable, tense), interest, engagement in day-to-day and social activities, sleep, appetite, energy, concentration, self-esteem, confidence in roles, ruminating, worrying, feeling on edge, a sense of dread.
2) How did you feel about others' reactions to what your relative did (family, neighbours, community, co-workers)?
Possible prompts: *Were they aware of the circumstances? Did you talk to them about your relative's actions? How do you think they saw you? Did your relationships with these people change in any way?*
3) What were the major difficulties you faced after your relative's actions?
Possible prompts: *How did you deal with or respond to these difficulties?*
4) Has the act of your relative changed the way you think/feel /see yourself/him /others/the
world?
Possible prompts: *How do you feel your personal/social/occupational life has been affected by what happened? How do you feel as a result of what happened to your relative?*

D. COPING, ACCEPTANCE AND SUPPORT

Purpose: To understand how the main caregiver coped and adapted to the act of his relative and what support she/he received.

IV. Could you please tell me how you coped with what your relative did?

1) Could you please describe what helped you cope after your relative's conviction?

Possible prompts: *What helped you get through? What has helped you to make sense of what happened? Has the way you cope changed over time? Were there particular sources of comfort/support? Did you seek any professional help or support at this time?*

2) What would you have done differently? What advice would you give to someone in your situation?
3) What type of support, if any, following your relative's actions would have been helpful to you?

   Possible prompts: *At what point following your relative's actions would this have been most beneficial? Were you aware of any professional support services?*

E. THE FUTURE:

Purpose: To understand the main caregivers' fears and hopes for their future and their relative's future.

V. Where do you go from here?

1) How do you see your future?
   Possible prompts: *What hopes/fears do you have?*
2) How do you see your relative's future?
   Possible prompts: *What hopes/fears do you have?*
3) How do you see your family's future?
   Possible prompts: *What hopes/fears do you have?*
4) What would need to happen for your hopes to be realised?

(16-10-2018, version 4)

Appendix Four: Demographic Information Sheet - Family Members

Demographic Information

Participant Identification Number:

Family Member

Age:

Gender (please indicate with an X):

Male_____Female _____

Ethnicity (please indicate with an X):

White

British_____Irish_____Other _____

Mixed

White & Black Caribbean_____White & Black African _____

White & Asian_____Other _____

Asian or British Asian

Indian _____ Pakistani _____ Bangladeshi _____ Other _____

Chinese _____ **Other** _____

Occupation (please indicate with an X):

Employed_____Unemployed_____Student _____

Other *(please specify)* _____

Relationship with relative: _____

Number of months since relative detained in secure facility: _____

(21-09-2018, version 3)

Appendix Five: Demographic Information Sheet - Relative

Demographic Information for the Relative

Participant Identification Number:

Age:

Ethnicity (please indicate with an X):

White

British_____Irish_____Other _____

Mixed

White & Black Caribbean_____White & Black African _____

White & Asian_____Other _____

Asian or British Asian

Indian _____ Pakistani _____ Bangladeshi _____ Other _____

Chinese _____ Other _____

(21-09-2018, version 3)

Appendix Six: Confirmation of University Sponsorship

UNIVERSITY OF BIRMINGHAM

FINANCE OFFICE

Ms Iliana Lilova
School of Psychology
University of Birmingham
Birmingham
Edgbaston, B15 2TT

Friday, 11 May 2018

Dear Ms Iliana Lilova

Project Title: A qualitative study of the psychological impact on family members of men admitted to medium secure facilities due to offending and mental health difficulties
Sponsor Reference: RG_17-233
ERN reference: ERN_17-1568

Under the requirements of Department of Health Research Governance Framework for Health and Community Care, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (http://www.birmingham.ac.uk/Documents/university/legal/research.pdf) and any appropriate College or School guidelines.

Finally please contact researchgovernance@contacts.bham.ac.uk should you have any queries.

You may show this letter to external organisations.

Yours sincerely

Dr Sean Jennings
Head of Research Governance and Ethics
Research Support Group

cc: (PI) Professor Alex Copello

University of Birmingham Edgbaston Birmingham B15 2TT United Kingdom
w: www.finance.bham.ac.uk

Appendix Seven: Ethical Approval

Health Research Authority

West Midlands - Edgbaston Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

18 October 2018

Miss Iliana Lilova
School of Psychology
University of Birmingham
Edgbaston
B15 2TT

Dear Miss Lilova,

Study title:	**A qualitative study of the psychological impact on family members of men admitted to medium secure facilities due to offending and mental health difficulties**
REC reference:	**18/WM/0181**
Protocol number:	**RG_17-233**
IRAS project ID:	**238846**

Thank you for your letter of 02 October 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will

be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

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

Document	*Version*	*Date*
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Confirmation of Insurance]	1	15 July 2017
Interview schedules or topic guides for participants	4	16 October 2018
IRAS Application Form [IRAS_Form_24052018]		24 May 2018
Letter from sponsor [Confirmation of sponsorship]	1	11 May 2018
Non-validated questionnaire [Demogrphic Qtrs]	3	21 September 2018
Other [Response letter to REC provisional opinion]	1	02 August 2018
Other [Participant Recruitment Flowchart]	1	20 July 2018
Other [Response letter to REC provisional opinion]	2	01 October 2018
Participant consent form [ICF]	2	19 March 2018
Participant information sheet (PIS) [PIS v4]	4	21 September 2018
Research protocol or project proposal [HRA Protocol]	2	19 March 2018
Summary CV for Chief Investigator (CI)		17 November 2017
Summary CV for student [Student CV]	1	17 November 2017
Summary CV for supervisor (student research) [CV Supervisor]	1	17 November 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/WM/0181	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely,

Mr Paul Hamilton
Chair

Email:NRESCommittee.WestMidlands-Edgbaston@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Dr Sean Jennings*
Emma Patterson Head of Research and Innovation at, Birmingham and Solihull Mental Health NHS Foundation Trust

Appendix Eight: Consent Form

Research site: Medium secure facilities at
BSMHFT Participant Identification Number:

Title of Project: **A qualitative study of the psychological impact on family members of men admitted to medium secure facilities due to offending and mental health difficulties**

Researcher: Iliana Lilova

Please initial box

1. I confirm that I have understood the information sheet dated 21 September 2018 (version 4) 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 during the research interview, without giving any reason, without my own or my relative's medical/social care or legal rights being affected. ☐
3. I understand that the research interview will be audio-recorded. ☐
4. I understand that following the research interview I will have one month for reflection. During this time, I may contact the researcher to withdraw my interview entirely or in part, without giving any reason, without my own or my relative's medical/social care or legal rights being affected. ☐
5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the NHS team responsible for me or my family member's care but only if any previously undisclosed issues of risk to me or my family member's safety should be disclosed. ☐
6. I understand that in line with the University's code of practice for research data, all data collected for the study will be preserved and accessible for ten years by the research team, after which it will be destroyed ☐
7. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes and that I will not be ☐

identifiable by my comments.

8. If I wish to see a copy of my interview transcript in the one month reflection period or if I wish to receive a copy of the findings once the study has finished, I agree to provide my contact details at the bottom of this form. ☐

9. I agree to take part in the above study. ☐

10. I agree for my contact details to be held securely in a locked cabinet at the University of Birmingham. Only authorised research personnel will have access to this cabinet. ☐

.....	.....	.....
Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

Participant's contact details:

……

……

……

……

……

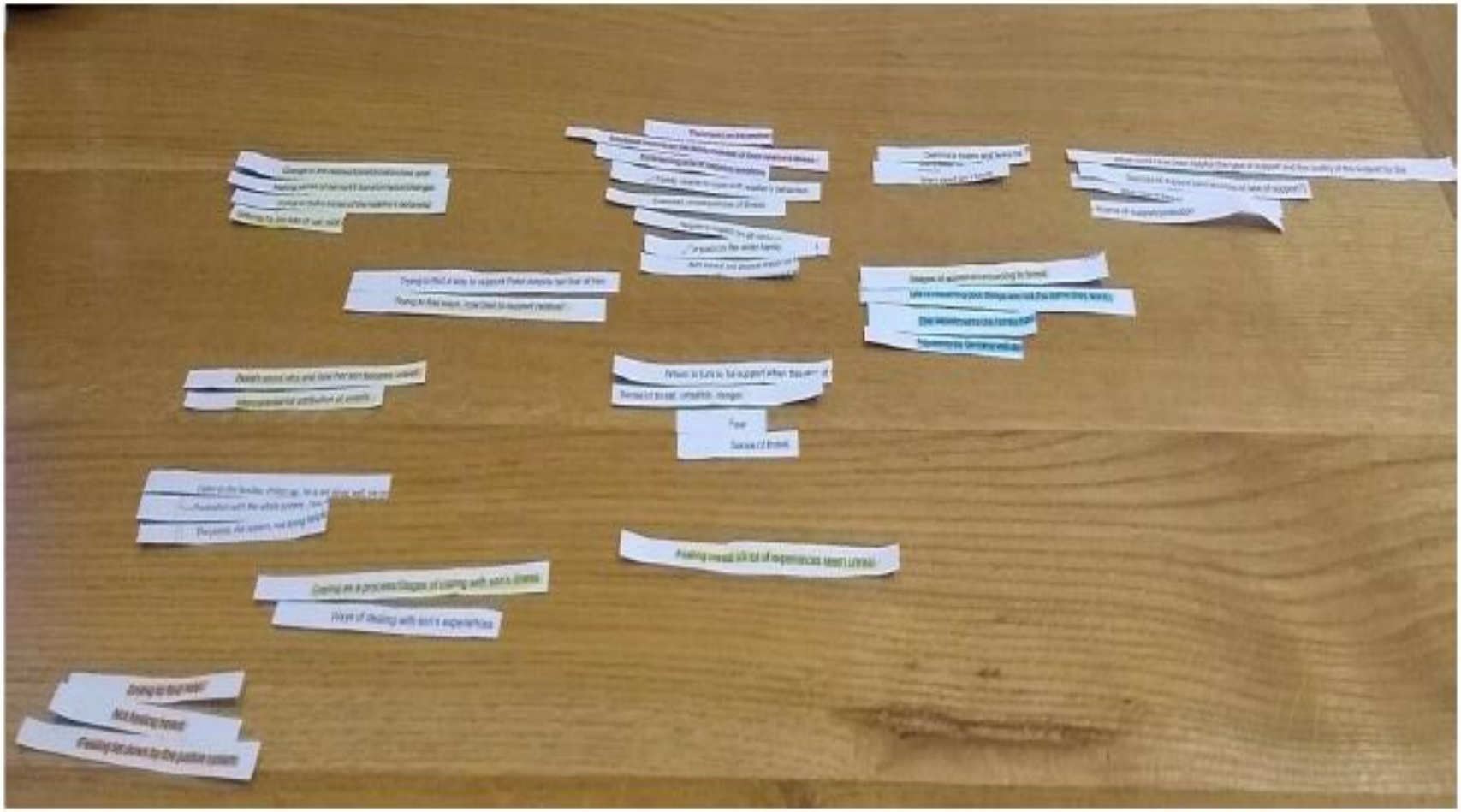
(19-03-2018, version 2)

After signing the form you will receive a copy of it. The original copy will be held in archive for 10 years in accordance with the University's code of practice for research.

Appendix Nine: Example of coding being condensed into emerging themes

Emerging Themes	Code	Transcript 1
Son as a threat	Vivid recollection with a lot of emotion. Painful to recall the event. A lot of conflicting emotions (love for her son and fear of him). Extreme fear for her own safety. Torn about calling the police on her son. Torn about asking Sean to leave the house but fears him.	2333 I'm here." I said "You know, I love you. Remember that. 234 I love you [cries]." And he just turned round and looked at 235 me with the most evilest look. Walked towards me. 236 'Cause I was really scared [sniffles] and he leaned over 237 the table, looked me dead in the eyes and said 238 "Something's gonna happen to you today." And I just 239 looked at him and then he backed up and he went back 240 upstairs. I ran out the house. Got in the car, drove down 241 the road, phoned the police, phoned Jessica*. I said I 242 can't live in the house anymore. I can't live like this. And 243 the police came and then I told them like you know, it 244 broke me to have to do it, but I said, "You have to leave 245 Sean. I can't live like this" [sniffles] And he was like, and 246 when anybody came in, even his older brother, if 247 anybody came and I said what was happening when 248 Sean wasn't around or if I said it in front of him.

Appendix Ten: Example of exploring connections between emerging themes



Appendix Eleven: Example of a table representing a superordinate theme

Superordinate theme: Prelude			
Subthemes:	**Emerging Themes:**	**Quote:**	**Page/Line:**
Awareness of deterioration in relative	Sudden transformation from polite to rude man	"And I thought this is not Sean, this is Sean isn't rude like this"	1-2/40-41
	Son intentionally wanted to hurt her?	"It was little, little things changing you know, and I thought why is he so rude?; " … and he was like saying things to me to try and hurt."	2/44; 2/45
	Son wanted to provoke her	"…and he started to be like, when he wouldn't answer the phone and he wouldn't, he wouldn't call me and I would start to get more worried. And I though is he taking, is he getting like a thrill out of me worrying."	2/49-51
	Grieving for the 'loss' of her son	"Not that nice, warm friendly way. He was changing into quite a cold person."	2/62-63
	Sinister change. Hard to reconcile with how he was before.	"And you think his personality was totally changing from a nice down to earth, loving, caring son to quite a cold nasty person."	2/73-74
Trying to make sense of relative's deterioration	External attribution of son becoming unwell - him smoking cannabis.	"And I knew on and off then that the time while he was at university he was smoking draw, I know that."	2/74-75
	External attribution of son becoming unwell - the abuse he suffered when he	"And I just can never forgive that [the abuse] and how he's paid for that and how he's got ill."	5/171

		5/171-172
	"You know, I know it's not the only thing [the abuse] the condition he's got but you know it's part of it."	
was 7 years old.	Internal attribution of son becoming unwell – his condition. Towards a more holistic view of son's illness.	

Appendix Twelve: Example of a table of a superordinate theme across participants

Superordinate theme across participants: Prelude				
Subthemes:	**Emerging Themes:**	**Quote:**	**Participant:**	**Page/Line:**
Trying to make sense of relative's deterioration	Attributes deterioration to the abuse and smoking cannabis.	"For I think that was the trigger. I think that was the trigger of, you know, smoking the draw, memories coming back it just overwhelmed him, he couldn't cope."	Gemma	7/243-245
	Attributes deterioration to cannabis, bad luck, fate, a test of her mental strength.	"…but then he started smoking and everything started to change."; "I think if he hadn't started smoking, he might have been alright…"; "He just had bad luck in his life.", "And I just think maybe it was his destiny…But to me I'm thinking it's a test…"	Liliane	2/32; 7/230-231; 7/206; 6/187-192
	Attributes deterioration to adverse childhood experiences.	"He was bullied at school, unmercifully right from the day he started school. ... He's had it really rough since he was this high bless him!"; "He suffered a lot since he was a child really. It started at school and then when his father becoming ill that made it worse and you know, then with me having postnatal depression it must have felt like his whole world falling	Rebecca	2/41-43; 4/104-106

		apart."		
	Attributes deterioration to being neglected in childhood.	"Of course, because they were neglected, they started to get into trouble."	Peter	1/17
	Attributed deterioration to a mental illness - schizophrenia.	"He has schizophrenia you see, he has schizophrenia and you could see that he was going nowhere, that he was gone …"	Anna	1/10-11