VOLUME 1:

SUBSTANCE USE AND ABUSE IN OLDER ADULTHOOD: EXPERIENCES OF OLDER-ADULT SUBSTANCE USERS AND ADULT FAMILY MEMBERS

A Literature Review and an Empirical Research Paper

Mandi Hodges

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University of Birmingham

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Abstract

This thesis is organised into two volumes. The first comprises a literature review and a research report which explored experiences related to substance use and misuse in older adulthood. The second volume is a collection of Clinical Practice Reports.

Volume One includes a literature review entitled "Older adults' experiences of substance use: a systematic narrative review of qualitative literature" and an empirical research paper which was designed to explore experiences of an adult with children who was also providing care or support for their parent who had an alcohol use problem.

Volume Two is made up of five reports. The first presents psychodynamic and cognitive formulations of depression and anxiety experienced by a 33-year-old woman, whilst the second is a case study of cognitive therapy completed with a 23-year-old man with obsessional thoughts and associated notions of inflated responsibility. The third report describes an evaluation of the proposed development of a community forensic service for people with a learning disability, with an evaluation of an intervention based on solution focused therapy with a 69-year-old woman experiencing depression and anxiety being the penultimate report. The volume ends with a summary of an oral presentation detailing the development of an outcome measure for a children's centre.

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Thank you.

Thesis Overview

This doctoral thesis is organised into two volumes. The first comprises a literature review and a research report which explored experiences related to substance use and misuse in older adulthood. The second volume is a collection of clinical practice reports.

Volume One focuses on substance use in older adulthood. Current research indicated that the number of older adults with a substance use disorder (SUD) has been increasing over recent years and is set to continue rising. A literature review was conducted which aimed to advance an understanding of the experience of older substance users and the meaning of substance use for older adults. Fifteen qualitative research articles published before January 2013 were collected for review. After providing an overview of the participant demographics and an assessment of the methodologies employed in the research, the review was organised around three substances; tobacco, alcohol and illicit drugs. Findings suggest that substance use was central to the older adult's life and altering their behaviour may involve challenging or changing aspects of themselves. Furthermore, the culture and context of substance use among older adults displayed some features specific to this age group indicating a need to understand this group separately from younger users. Recommendations are made for treatment programmes, for health initiatives and for future research. It was anticipated that the literature review would be submitted to Substance Use and Misuse for publication (see Appendix 1).

This volume also includes a report of a study which was designed to explore experiences of an adult with children who was also providing care or support for their parent who had an alcohol use problem. The findings indicated that the participants appeared to face a number of conflicts or dilemmas in relation to their relationship with their parent. It was concluded that the experiences of adult family members caring for a problem-drinking parent appeared to be similar to those of other family members affected by a relative's substance abuse, however, the participants' particular relationship to the drinker also brought about a number of contrasts from those with a different attachment or relationship. Furthermore, the specific conditions of the situation indicated differences between the participants in the study and family members providing support to an elderly parent with older-age-related difficulties. The findings reaffirmed the need for support for family members of

people with a substance use problem. It was anticipated that the paper would be submitted to Families, Relationships and Societies for publication (see Appendix 4).

An executive summary of the literature review and the empirical research paper is also contained in Volume One, to be used as a public domain briefing document.

Volume Two begins with a description of psychodynamic and cognitive formulations of depression and anxiety experienced by a 33-year-old woman. Two formulations of the client's distress are presented, one from a psychodynamic perspective and the other grounded in a cognitive approach. The psychodynamic formulation is structured in terms of Malan's (1995) Triangles of Person and Conflict. The cognitive formulation is organised into a longitudinal account and current maintenance cycles are proposed. The report ends with a critical appraisal of the formulation process from the two perspectives, paying particular attention to how key features of the theoretical approach and methods of assessment may have influenced the formulation.

The second report describes a case study of a 23 year-old man with obsessive compulsive disorder with a strong presentation of over-responsibility. A personal history provided in the report details the context of the obsessional intrusive thoughts and associated compulsive behaviours. The report describes the assessment process before detailing the case formulation. The intervention employed mindfulness techniques to aid response prevention and cognitive therapy to redress an inflated sense of responsibility. Pre- and post-treatment scores on two assessment scales are presented which depict a successful intervention. The report concludes with personal reflections on the work.

An evaluation of the proposed development of a community forensic service for people with a learning disability is included in Volume Two. Two focus groups were conducted with professionals who work in the field and the discussions were subject to a Thematic Analysis. The concerns raised in the focus groups mirrored those reported in relevant published literature and the proposed new service appeared to meet many of the recommendations laid out in national reports.

Further direct clinical work is reported in the volume with the evaluation of an intervention based on solution focused therapy with a 69-year-old woman experiencing depression and anxiety. A formulation informed by systemic theories is provided. The client's distress was measured by completing the Hospital Anxiety and

Depression Scale on a weekly basis for five weeks before regular contact began and throughout the seven-week intervention period. Solution Focused Therapy was the main approach to therapy used in the intervention. At completion the data were analysed using a Simulated Modelling Analysis technique. Overall the results were not statistically significant, suggesting a limited effect of the intervention on the client's distress. This is in contrast with the seemingly clinically successful piece of therapeutic work. The discussion considers possible reasons for these results and suggests adaptations to the study.

The volume ends with a summary of the development of an outcome measure for a children's centre. The context for the work is provided before a description of the process of developing a questionnaire. Brief details are provided of the findings from a survey using the questionnaire and recommendations are offered.

References

Malan, D. H. (1995). *Individual psychotherapy and the science of psychodynamics. 2nd Ed*. London: Arnold

VOLUME 1

Literature Review: Older adults' experiences of substance use: a systematic narrative review of qualitative literature

Empirical Research Paper: "How do I tell my children about what my mum's like?": Conflict and dilemma in experiences of adult family members caring for a problem-drinking parent.

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**Clinical Practice Report 3: An Evaluation of the Proposed Development of a
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Clinical Practice Report 4: The Evaluation of an Intervention Based on Solution Focused Therapy with a 69-Year-Old Woman Experiencing Depression and Anxiety

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A Case Study of Cognitive Therapy Completed with a 23-Year-Old Man with Obsessional Thoughts and Associated Notions of Inflated Responsibility

An Evaluation of the Proposed Development of a Community Forensic Service for People with a Learning Disability

The Evaluation of an Intervention Based on Solution Focused Therapy with a 69-Year-Old Woman Experiencing Depression and Anxiety

Older adults' experiences of substance use: a systematic narrative review of qualitative literature

Abstract

Fifteen qualitative research articles published before January 2013 were collected for review. After providing an assessment of the methodologies employed, the review is organised around three substances; tobacco, alcohol and illicit drugs. Findings suggest that substance use is central to the older adult's life and altering their behaviour may involve challenging or changing aspects of themselves. Furthermore, the culture and context of substance use among older adults display some features specific to this age group indicating a need to understand this group separately from younger users. Recommendations are made for treatment programmes, health promotion initiatives and future research.

Introduction

In the early 1990's Moos, Mertens and Brennan (1993:485) reported that "adults age 55 or older comprise a substantial proportion of substance abuse inpatients" in the USA, with alcohol being the most common substance of abuse (see also Crome & Crome, 2005). Indeed, the authors argued that "alcoholism" had been reported as "the second most frequent reason that older patients are admitted to psychiatric inpatient units" (Moos et al.., 1993:479). Over the intervening years the number of older adults who use substances of abuse has increased (Abrams & Alexopoulos, 1998; Grover, Irpati, Saluja, Basu & Mattoo, 2008; Moos, Schutte, Brennan & Moos, 2009) and is set to continue increasing, with Han, Gfroerer, Colliver and Penne (2009) predicting a doubling of the number of older adults with a substance use disorder in the USA by 2020. Moos et al.. (2009) examined changes in alcohol consumption by a group of older adults in the USA over a twenty year period. Their results suggested that although the overall level of alcohol consumption tended to decline as people aged, still at ages 75-85 years nearly a third of women and nearly half the men were drinking over the recommended guidelines. This was associated with an increased likelihood of alcohol-related problems since factors such as the potential interaction between alcohol and other medication and altered metabolism in older age heighten the risk of harm or negative implications of alcohol use in older adults (Dunne & Schipperheijn, 1989; Han et al.., 2009). These risks are obviously increased with higher levels of alcohol use. The increase in the number of older adults who use substances problematically is not confined to alcohol use or to the USA but also includes illicit drug users and other countries (Beynon, McVeigh & Roe, 2007; Fahmy, Hatch, Hotopf & Stewart,2012; Haarni & Hautamaki, 2010)

Reasons for this increase in numbers of older substance abusers are uncertain, and there may be many. For example, the increased numbers of people born during the 'baby boom' period are now reaching their mid-sixties so there are simply higher numbers of all types of people reaching the 'older' age category. Linked to this is an observed increase in the use of psychoactive substances by this cohort compared with previous generations (Abrams & Alexopoulos, 1998; Gfroerer, Penne, Pemberton, & Folsom, 2003) including a particular increase between the years of 1965-1973 in what was then seen as the 'fashionable' drug, heroin (Kinlock, Hanlon & Nurcon, 1998). Whilst most people discontinued use over the years, many maintained use and some

survived to progress through the generations and reach older age (Beynon et al..,
2007).

Despite this increase being reported in research, O'Connell, Chin,
Cunningham, & Lawlor (2003) and Gossop & Moos (2008) argue that, in practice,
rates of older people with a substance use disorder may be underestimated due to a
number of factors including underdetection or misdiagnosis. Through reviewing
relevant research evidence Dar (2006) and O'Connell et al.. (2003) identified and
detailed barriers to identifying alcohol use disorders in older adults. Problems may be
masked by the aging process itself since many factors often associated with old age
are also symptoms of alcohol problems, for example, cognitive impairment including
memory problems, depression, falls and accidents. Other barriers described included
societal myths (such as the belief that people naturally reduce their alcohol intake as
they get older therefore few older adults drink heavily), attitudes of healthcare
professionals (who are reported as appearing reluctant to ask older people about their
alcohol use) and finally inadequate or inappropriate methods of screening for and
assessing substance use disorders in older adults (Derry, 2000). Again, this is not
confined to alcohol with similar barriers being reported for other types of substance
abuse (Crome and Bloor, 2005b). The authors argue that, as a result of this lack of
identification, insufficient or inappropriate support is offered, while O'Connell et al.
(2003) go as far as to suggest that "therapeutic nihilism" (p665) exists in relation to
elderly adults and substance use disorders. Dar (2006) recommended that older people
should routinely be screened for alcohol use problems and argued that commonly-
used treatment approaches such as brief interventions, drug-maintained abstinence
and psychological treatments can all be appropriate modes of intervention for older
adults. Based in the USA, Moos et al.. (1993) noted that although a significant
percentage of older adults admitted to medical centres were diagnosed with an
alcohol-related problem, they were unlikely to receive inpatient or outpatient
specialist treatment for substance misuse problems. Instead, the services offered were
focused on medical management of the problems. The authors argued that there was a
need to develop substance abuse treatment programmes for older adults and
recommended more use of specialist substance misuse outpatient aftercare services
for older adults.

In a review of the literature on treatment for older people with substance use
problems, Moy, Crome, Crome and Fisher (2011) concluded that older people are able

to respond positively to treatment and "do not achieve worse outcomes than their younger counterparts" (p220). However, a caveat to their encouraging conclusion was that the review was based on very limited evidence and they recommended that more research needs to be conducted.

For many years Crome and colleagues have been calling for better substance misuse services for older people (Crome & Day, 1999; Crome & Bloor, 2005a; 2005b; 2006). Evidence suggests that drug abuse is a problem in the older generation (Crome & Crome, 2005) and that older people are able to respond to treatment (Moy et al.. 2011) yet, as Crome and Bloor (2005a) complain, there is no designated service in the UK for older people with a substance use problem. They conclude that "older people remain an invisible, hidden, stigmatised and neglected group which is being 'misused' in the sense that they are not being exposed to, or evaluated on, the rapidly developing treatment portfolio for substance misusers" (p132). In addition to the problems of identification outlined, in order to develop a service to help older people manage and possibly alter their substance use, it would be important to understand the meaning of substance use for older adults. The present review of the literature attempts to gain an understanding of the experiences of substance use from the perspective of the older user.

The main objective of this review is to gain an understanding of the experiences of older adults' substance use and the meanings attached to their use. Since qualitative research aims to capture people's own perceptions and versions of their world (Denzin & Lincoln, 2005; Marks & Yardley, 2004), only qualitative research has been included.

Method

This review examines older people's accounts of their substance use. The following procedure was followed in order to collect literature for the review.

Inclusion Criteria.

Articles were included according to the following criteria.

- ➢ Older adults – specific age not predetermined but the article needed to identify the participants as older adults or words to that effect.
- ➢ A focus on current or past substance use
- ➢ Qualitative research methodology

Exclusion Criteria.

Articles were excluded from the review if they met the following exclusion criterion.

➢ Prescription drug use

The topic of substance use and abuse has long included nicotine/tobacco, alcohol and the varied category of illicit substances. These substances most regularly appear amongst those reportedly often consumed despite negative health effects or continue to be used far beyond the point at which they could be associated with negative outcomes. They are also often bound up with a person's self-categorisation or identity, for example as 'a smoker' or a 'real-ale drinker'. They all also typically have a social aspect to their use. However, they are not the only substances abused by older adults who may also misuse prescription or over-the-counter medication. These latter substances appear to lack the social and 'identity' aspects that typically accompany the use of the former substances. Hence, in order to cover as broad a range of substance use as possible but to avoid repeating recently published work (Cooper, 2013) or attempting to synthesise research on activities with little common ground studies on tobacco, alcohol and illicit drug use were included but prescription and over-the-counter medication were excluded. In a recent review of over-the-counter medication, Cooper (2013:101) identified only two qualitative articles and reported a "lack of qualitative methods that may be appropriate for exploring individual perspectives", hence, inclusion of research on over-the-counter medication may have made a limited contribution to the current review.

Search Strategy.

Databases were searched until December 2012. The databases used were PsycINFO, Social Sciences Citation Index, Sociological Abstracts, JSTOR and Web of Science. A search strategy was employed to conduct various searches using 'older adults', 'elderly', 'substance', 'drinking' and 'smoking' as search terms. The searches were limited to articles published in English language, qualitative studies and published in peer-reviewed journals. An example of the search strategy is provided in Appendix 2. The abstract of each of the resulting articles was then read by the current author and papers were rejected based on the inclusion and exclusion criteria. The reference list of each of the remaining papers was then searched for any other relevant articles. Fifteen research articles were included in the review as detailed in Table 1.1.

Before reviewing the research findings, the methods used to conduct the research were considered. The following section reports on the participants' demographic characteristics, the methodologies employed in the studies reviewed and the quality of the research.

Table 1.1. *Research articles included in the review*

Author (Year)	Substance	Place	No. of Participants	Data collection	Analysis
Anderson & Levy (2003)	Poly drug	USA	40	Interview	Grounded Theory and constant comparative method
Broeri (2004)	Heroin	USA	38	Interview	Grounded Theory and constant comparative method
Broeri, Sterk & Elifson (2006)	Heroin and methamphetamine	USA	65	Interview	Modified Grounded Theory
Broeri, Sterk & Elifson (2008)	Heroin	USA	29	Interview	Modified Grounded Theory
Haarni & Hautamaki (2010)	Alcohol	Finland	31	Interview	Content Analysis and biographical analysis
Joseph (2012)	Alcohol	Canada	27	Observation and Interview	Ethnography and inductive coding
Kim (2009)	Alcohol	Canada	19	Focus group	Constant Comparative Method
Levy & Anderson (2005)	Poly drug	USA	40	Interview	Grounded Theory and constant comparative method
Parry, Thomson & Fowkes (2001)	Tobacco	UK	22	Interview	Described steps but 'method' not identified
Parry, Thomson & Fowkes (2002)	Tobacco	UK	22	Interview	"Analysed thematically"
Pope, Wallhagen & Davis (2010)	Illicit drugs	USA	6	Interview	Grounded Theory
Roe, Beynon, Pickering & Duffy (2010)	Illicit drugs	UK	11	Interview	Thematic content analysis
Schofield, Kerr & Tolson (2007)	Tobacco	UK	22	Interview	Used theoretical model as framework for analysis
Smith & Rosen (2009)	Methadone	USA	24	Interview	Content analysis and comparative technique
Tolvanen & Jylha	Alcohol	Finland	254	Interview	Discourse Analysis

(2005)

Demographic Characteristics, Methodology and Quality

Participants.

Participants in the studies reviewed were all identified as 'older adults' with some variant of this definition appearing in the key words section of thirteen out of the fifteen papers. However, this meant different things in different papers. The participants in papers focused on illicit drugs were typically younger than in the other studies. This was justified in all of the reports with the explanation that people who have continued to be injecting drug users do not generally reach what may normally be considered 'old age'. People over 50 were recruited to the studies and described as 'older adults' but the series of papers published by Boeri and colleagues (Boeri, 2004; Boeri, Sterk & Elifson, 2006 and 2008) drew on a data set which set out to explore the 'baby boom' generation. Using the parameters set out by Boeri (born between 1945 and 1965), this made the youngest eligible person 35 years old at the time of collecting data. One participant was this age. In the studies on alcohol and tobacco, the participants were all over the age of 50, with the range spreading to people in their 90s.

The number of participants varied somewhat (see Table 1.1). The research by Pope et al.. (2010) was based on just six participants, while Tolvanen & Jylha (2005) drew on a data set of 254 interviews. The remaining papers had between eleven and sixty-five participants.

In all three articles focusing on smoking the female participants outnumbered the men. This trend was reversed in all papers focused on drug use, however, some were almost half of each with Boeri, Sterk & Elifson (2008) recruiting fifteen men and fourteen women. Alcohol studies provided a mixture with Haarni & Hautamaki (2010) studying sixteen women and fifteen men, but Joseph (2012) including an all male sample.

African American and Afro-Caribbean participants made up the majority of the sample with 8 of the 11 papers that identified ethnicity including some, or their entire sample from these two ethnic groups. Of the remaining seven papers, two included only Finnish participants, one only Korean people and four did not identify the ethnicity of their sample. These four studies were all conducted in the United Kingdom; three in Scotland and one in England.

The sample of participants was split between those receiving treatment for substance use disorders or related illnesses and those not in treatment. All three studies focused on tobacco smoking recruited people who were receiving treatment for a smoking related disease. Conversely, none of the four alcohol focused studies included participants in treatment or who claimed to drink problematically. Both Haarni & Hautamaki (2010) and Kim (2009) accessed their participants via services for older people, whilst Joseph (2012) visited a sporting ground to recruit an opportunity sample and Tolvanen & Jylha (2005) contacted participants of a previous general mailing survey. The illicit drug focused studies were divided. The three papers produced by Pope et al.. (2010), Roe, et al.. (2010) and Smith & Rosen (2009) interviewed people who were in contact with drug treatment services. The remaining five papers drew on only two data sets, neither of which included drug users in receipt of treatment. The opportunity samples were accessed via the researchers spending time in places frequented by drug users.

Methodology.

There was a heavy reliance on individual interviews as a means of collecting qualitative data, with all except one using this method. Kim (2009) ran focus groups to generate data whilst Joseph (2012) supplemented her interviews with ethnographic field notes of observations.

A version of Grounded Theory (Charmaz, 1983; Corbin & Strauss, 1990; Glaser & Strauss, 1967), typically using a constant comparative method, figured strongly in this group of articles with seven of the fifteen articles using this approach (see Table 1). Discourse Analysis (Potter & Wetherell, 1987) and Ethnography (Spradley, 1979) underpinned the approach in two of the articles, two stated that they had conducted a content analysis, with the remaining papers not identifying a particular theoretical or methodological approach to analysis. The level of description of the analysis was rather variable both in the description of the general theoretical approach to analysis and in the description of the actual analysis performed with the specific data.

Quality Assessment.

      Quality assessment criteria.

There has been much discussion and debate about whether assessment or evaluation criteria for qualitative research are possible, necessary or even desirable (Hammersley, 2008; Seale, 1999). Despite the assertion that, due to methodological pluralism within qualitative research, a set of criteria could, and possibly should, not be developed (Smith, 1984; Smith & Deemer, 2000), some principles for assessing the quality of the work have been proposed (see for example, Cesario, Morin & Santa-Donato, 2002; Hammersley, 2008; Yardley, 2000). When producing a systematic literature review it is arguably important to consider and indicate the relative quality of the work being reviewed, and, for the sake of consistency, some sort of criteria may be of value. A relatively recently proposed method, which imposed very little on the studies and therefore allowed for theoretical and methodological differences, was provided by Hammersley (2008). He proposed considerations in assessing the adequacy of the research report and the significance of the research findings. Details of the criteria can be found in Tables 1.2 and 1.3 (see also Appendix 3).

Table 1.2	
Considerations in assessing the adequacy of research reports.	
The following considerations cover both clarity and sufficiency as standards:	
1. The clarity of the writing	a. Consistency of terms used
	b. Are definitions provided where necessary?
	c. Are sentences sufficiently well constructed to be intelligible and unambiguous?
	d. Is there use of inappropriate rhetoric?
2. The problem or question being addressed	a. Is this clearly outlined?
	b. Is sufficient rationale provided for its significance?
3. The formulation of the main claims	a. Are these made sufficiently clear and unambiguous?
	b. Are the relations with subordinate claims (including evidence) made sufficiently explicit?
	c. Is the character of each claim (as description, explanation, theory, evaluation or prescription) indicated?
4. The formulation of the conclusions	a. Is there a distinction between main claims about the cases studied and general conclusions?
	b. Is the basis for the conclusions signalled?
5. The account of the research process and of the researcher	a. Is there sufficient, and not too much, information about the research process?
	b. Is there sufficient, and not too much, information about the researcher?

(Adapted from Hammersley, 2008: 162)

Table 1.3
Considerations in assessing the significance of research findings. (See Appendix 3 for further details)

As regards validity, the following considerations might be involved:	
1. The main claims and evidence	a. Are the main claims plausible or creditable enough to be accepted at face value?
	b. If not, is evidence provided?
2. The relationship between the findings and the conclusions	a. Are empirical generalisations sufficiently plausible or creditable to be accepted?
	b. Are theoretical statements sufficiently plausible or creditable to be accepted?
In relation to relevance, the considerations might be:	
1. The importance of the topic	
2. The contribution of the conclusions to existing knowledge	

(Adapted from Hammersley, 2008: 162-163)

Despite the criteria being clear and extensive they also possibly allow for a degree of bias since each person brings their own understanding and level of knowledge or expertise when evaluating each of the research articles. In order to attempt to gain a measure of inter-rater reliability another contributor to the review could read, evaluate and discuss the literature together to produce a joint assessment. In this review the assessment criteria, the papers under review and particular areas of interest or concern in specific articles were discussed between the researcher and the supervisor but only the researcher read all of the articles reviewed.

Adequacy of the research report.

Across the set, the papers were typically well written with a level of clarity sufficient for readers to understand the claims and arguments being made. Activities and terms which may not be familiar to all readers were generally explained well.

There was some variation in how well the problem or question being addressed was identified. Most of the articles identified the aims of the study and provided a rationale, however, whilst some papers indicated that little other research had focused on the topic, they did not then clearly explicate why that particular area should be studied in the way that they had. Notable papers were Boeri et al.. (2006), Joseph (2012), Parry et al. (2002), Roe et al. (2010) and Tolvanen & Julha (2005) which provide a weaker rationale for their work than the authors of the other papers.

All of the authors provided some data extracts to support the main arguments they were presenting in the findings section of the article. Largely, the authors typically explained how the extracted quotation illustrated the analysis, however, there were three exceptions. Schofield et al. (2007) identified a theoretical model which they used to analyse the data, describing it as "question driven, seeking evidence of each of the elements in the Health Belief Model" (p1729). The main point of the analysis was to identify the participants' health beliefs, however, there was often quite a weak match between the quotation provided and the claim being made, and at other times the quotation was left to 'speak for itself' with little analysis attached. In this article the framework appeared to limit what could be said about the data.

Largely the conclusions drawn by the authors were appropriately formulated from the analysis presented, however the work of Pope et al. (2010) was a notable exception. They aimed to identify social processes involved in older African American's drug use but appear to have attempted to tell a bigger story than the data could support. The analysis was quite limited with an inappropriate use of rhetoric, including using their own 'wondering' to support their argument. There was a very close association between case examples and generalised conclusions. With only six participants, a somewhat weak analysis, and a reliance on rhetoric rather than evidence, one could argue that the conclusions needed to be much more tentative.

Descriptions of the research process and acknowledgement and discussion of the researchers' position and role in the process were limited across the studies reviewed. Many had identified which approach or method they had used, with some describing general steps, but there was a dearth of specific explanation of the steps taken to analyse the data in the study. Better examples of an acknowledgement of the researcher in the process were Boeri's (2004) explanation of how she gained acceptance from her participants with a disclosure of her past experiences and Joseph's (2012) description of herself and her interactions and relationship with the participants. Unfortunately none of the other researchers provided a reflexive account.

Significance of the research findings.

The findings of most of the research studies were plausible and creditable enough to be accepted at face value but also had evidence to support the claims. As noted previously, papers by Pope et al. (2010) and Schofield et al. (2007) were weaker

than the other papers in this regard as the evidence sometimes appeared to be tenuous support for the claims being made.

Typically papers offered strong conclusions, relating findings to a theoretical framework and, most often, making recommendations to clinical practice for older substance users. All papers managed to demonstrate the importance of the general topic, with all pointing to an increase in the numbers of older substance users and a limited understanding of the implications of that increase. Overall, the papers were generally successful in helping the reader to place value on the knowledge the research had contributed.

Synthesis of the Research Findings

The following description of the research findings is organised and discussed in depth in the three groups of substances studied, namely tobacco, alcohol and illicit drugs. The tobacco sub-section examines three articles whilst alcohol and illicit drugs examine four and eight respectively.

Tobacco

The three articles which explore older people's experiences of smoking all focus on people with a smoking-related disease; two arterial disease (Parry, Thomson & Fowkes, 2001; 2002) and one chronic obstructive pulmonary disease (Schofield, Kerr & Tolson, 2007). All of the participants in the Parry et al. (2001; 2002) papers and the majority in the Schofield et al. (2007) study were current smokers. All of the three studies were conducted in Scotland, UK, so there may be a British bias in the findings. The articles by Parry et al. (2001; 2002) were drawn from the same data and employed the same qualitative methodology. Participants were interviewed as part of a two-year study into "Life Course Influences on Patterns of Persistent Smoking" (Parry et al., 2001: 1338). The first of the two papers explored older smokers' reasons for smoking and their beliefs about dependency and smoking. Respondents were categorised by level and pattern of smoking and by their own assessment of dependence giving rise to three groups; dependent smokers, non-dependent smokers and smokers with dependent usage who saw themselves as non-dependent. The data were then analysed in these three groups to detect patterns of ways of talking and beliefs about smoking.

In their second article Parry et al. (2002) explored the changing cultural context of smoking through accounts of people who have been smoking for over forty years. Accounts indicated that the move in acceptability of smoking as a social activity may be the most influential change for the smokers interviewed. For many this had resulted in a reduction in their level of smoking, however, a regrettable outcome for many was that they socialised less and associated smoking with increasing levels of social isolation.

Schofield et al. (2007) set out to explore smoking-related health beliefs of older smokers. In order to achieve this they interviewed twenty-two older smokers recruited through a city hospital's outreach service for people with COPD. The study did not employ a particular qualitative method of analysis but instead used the Health Belief Model (Becker, 1974) as a framework for analysis, with the data being searched for the main concepts of the model. The authors concluded that participants continued to smoke despite largely perceiving smoking as a threat to their health. Participants were reported as citing various barriers to stopping smoking, including making reference to the 'addictive' nature of smoking, indicating smoking as being a helpful resource if the person was upset, and suggesting that 'at their time of life' and after the length of time they had been smoking, stopping could potentially do "more harm than good" (p1730).

Older people less likely to stop smoking.

The participants in each of the three studies were reported as proposing clear barriers to stopping smoking, leading all of the researchers to conclude that older people were less likely than young people to want to stop smoking. In all of the studies participants reported perceived benefits to smoking; for example, Schofield et al.'s (2007) participants reported that it helped them to manage symptoms of their illness ("my breathing's even better"; "it seems to help me cough it up". p1730) while participants in all of the studies cast smoking as being a positive resource to help with coping and relaxation. Apart from coping with health difficulties, perceived benefits were also reported related to coping with loss of significant others and increased feelings of social isolation. Their many years of 'addiction' were flagged up by participants as a reason why considering stopping would be particularly difficult for them. Due to their age and years of smoking participants were reported as indicating that there was little need to justify their smoking or entitlement to smoke beyond their

longstanding dependence. Finally there appeared to be little perceived benefit to stopping at their age. All participants had a diagnosis of a smoking-related disease therefore many expressed that 'the damage was already done' and there would be little health benefit for the time they still had left to them.

Smoking as a functional behaviour.

Whilst some people talked in terms of smoking being a dependent or 'addicted' behaviour, speakers in all three studies cast smoking as a functional behaviour. The functions included reward after completing chores, coping with circumstances of older age such as boredom due to reduced activity, loneliness after retirement or loss of a spouse and failing health. Although participants talked about the changes in social acceptability of smoking over the years with them going from 'being like everyone else' to 'being an outcast', they reported that there were still some social elements to smoking and could still be a shared interest and activity.

Alcohol

Unlike the groups of articles focused on tobacco and those focused on illicit substances, alcohol was not automatically cast as a substance that is socially sanctioned, however, many participants spoke in terms of it being a substance whose use should be regulated. A further contrast between the alcohol studies and the other two groups of articles is that the participants in this sub-section did not consider their use to be problematic or were not receiving treatment for a substance-related illness. In one of the four studies (Haarni & Hautamaki, 2010) a framework for analysis was employed which was formulated around the notion of control over drinking, categorising people as controlled or uncontrolled drinkers and examined different characteristics of groups of drinkers. Since this analysis was somewhat different from the method of analysis in the other studies, this made it slightly more difficult to include in the synthesis. Nevertheless, four clear, broad findings were apparent from the review; cultural differences, gender differences, drinking as a social activity and alcohol related to health.

Cultural differences.

Unlike the other papers on older adults' substance use examined in this review, the research on alcohol had a clear cross-cultural aspect to it. Two of the

articles were conducted in Finland exploring the experience of native people whilst the other two were based in Canada exploring the experience of two different groups of non-native people. Taken together, papers by Haarni & Hautamaki (2010) and Tolvanen & Jylha (2005) present an important change in Finnish attitudes to drinking over time. The first of the two articles (Tolvanen & Jylha, 2005) presented accounts of people aged over 90 years where talk of drinking alcohol was saturated with heavy moral meaning and speakers were keen to portray themselves as decent, moderate people contrasted with others who drank immoderate amounts or drank simply for pleasure. Haarni & Hautamaki's (2010) study, published five years later with people who were aged 60-75 years represented a different generation of the same nationality. A more 'liberal' view of alcohol use was apparent in the talk, with the Finns reportedly finding it much more acceptable to drink regularly. There was still a clear emphasis on moderate drinking, with intoxication something to be avoided. Even people who spoke of drinking more when they were younger were portrayed as aiming to moderate their drinking as they aged, with increased skills in controlling alcohol use and avoiding drunkenness being reported by the authors as developing with age.

The two studies provided an interesting change in apparent views on alcohol use over time, however, Kim (2009) presented the influence of culture in changes in alcohol use for Korean immigrants in Canada. The findings indicated that the speakers' views on alcohol remained the same but their drinking behaviours changed due to differences in pricing and restrictions across the two countries, resulting in the Korean men drinking less than they would have in their homeland. Similarly, Joseph's (2012) Afro-Caribbean participants living in Canada maintained their homeland cultural views on alcohol consumption in their adopted land, and often bought certain brands of alcohol to celebrate their national affiliations.

There were very apparent cross-cultural differences in the use of alcohol, the meaning of drinking and opinions of drunkenness across the studies. Some groups were seemingly more tolerant of drunkenness, which reportedly, may be used as a mask for failing health or abilities due to older age. Indeed, for some, it apparently would be better to be considered drunk than to be old (Joseph, 2012). Other groups were much less tolerant of drunkenness, especially for older people and it was unilaterally viewed as unacceptable for women.

Gender differences.

Gender differences in alcohol use are a regular finding in research (Ahlstrom, Bloomfield & Knibbe, 2001) and were also apparent across the studies of older drinkers. Three of the four papers explicitly discussed gender differences or gendered themes. Haarni & Hautamaki (2010) conducted their study as part of a larger project on 'ageing and alcohol' (Haarni & Hautamaki, 2008) and focused on age being the relevant demographic, therefore they did not draw attention to any possible gender-related issues, if such phenomena were apparent in their data. The findings of the remaining studies indicated that there was a consistent view that women should drink less than men, if at all. Heavy alcohol drinking was portrayed as being the reserve of men and not a female activity, therefore women were generally excluded from the male drinking occasions. Joseph (2012) reported that Caribbean-Canadian men took advantage of drinking events as being an opportunity to escape their wives, (grand)childcare responsibilities and other domestic duties. Joseph further argued that engaging in this male-dominated activity allowed the older men to reinstate their masculinity which may be challenged by an ageing body which may no longer have the strength and speed associated with younger men which they demonstrated in years past.

In many cases the older women were seen as 'regulators and moral guardians of alcohol use' (Tolvanen & Jylha, 2005) both for men and for women, either explicitly or indirectly. Kim (2009) reported changes in Korean immigrants' drinking occasions in their new country to include more events when the man's wife was present. This often reduced the men's enjoyment of the drinking event, with one speaker commenting that the "alcohol is not tasty at all" (p348) when his wife is present.

More explicit regulation of alcohol was revealed by Tolvanen & Jylha (2005) who exposed older Finnish women's harsh judgement of other women's drinking. Whilst moderate drinking in men was deemed acceptable and even heavy drinking could be tolerated as long as he had other redeeming qualities, drinking by women was harshly condemned. Problematic drinking in men or men's bad behaviour when drunk was often constructed as being the force of alcohol as a personified entity with the power to control the man's behaviour, exonerating him of accountability. Women's behaviour, however, was never cast as such and she could be morally judged for her behaviour.

Gender differences in reasons for drinking were reported by Kim (2009). Korean men reportedly viewed alcohol as a regular part of a meal, they also placed it central to social gatherings and an essential component of parties and celebrations, whereas, while women agreed that alcohol was not misplaced at mealtimes and social occasions, they considered it less crucial. Unlike men, the older female Korean participants spoke of using alcohol in relation to their psychological mood or to even out their emotions. If drinking to lift a low mood or to celebrate a good feeling, the women may drink alone at home, which is not something the men claimed to do.

Drinking as a social activity.

In all of the papers drinking alcohol was considered a social activity to a greater or lesser degree, as indicated in the above two sections. For some, drinking was a central activity to the event (Joseph, 2012; Kim, 2009) but, for others, whilst drinking for pleasure was both implicitly and explicitly defined as indecent, moderate alcohol use as part of a social event was acceptable (Haarni & Hautamaki, 2010; Tolvanen & Jylha, 2005). In such cases alcohol was cast as a 'social lubricant' to make interaction easier and encourage conversations to flow. Cultural and gender differences were apparent in this theme but in each paper there was typically an association between alcohol and social activity portraying the consumption of some alcohol justifiable, understandable and 'normal'.

Alcohol related to health.

Speakers in all of the four studies made some reference to a relationship between alcohol and health. Alcohol taken in low quantities was generally imbued with some 'medicinal' properties; for example, Tolvanen & Jylha's (2005) Finnish participants spoke of drinking an occasional glass of brandy as this was considered good for the health of older people. Similarly, Kim's (2009) Korean participants reportedly drank wine in the belief that a glass a day is good for the heart. These beliefs were corroborated with reference to being given such advice by doctors, medical advisors and family. Crossing cultural divides was the notion that alcohol could be an effective reliever of psychological difficulties, with people taking alcohol to combat anxiety, stress, unhappiness and loneliness (Haarni & Hautamaki, 2010 and Kim, 2009)

It was also generally agreed that too much alcohol was bad for the body, however, this was viewed very differently with some only seeing it in negative terms and others intimating its advantages. Tolvanen & Jylha's (2005) oldest old participants used their advanced age as evidence of their limited consumption of alcohol, arguing that they may not have reached such an age if they had drunk more in the past. Conversely, Joseph (2012) claimed that her participants used alcohol consumption as a mask for a body deteriorating with older age.

Illicit Substances

Eight of the fifteen papers focused on illicit substances; two solely on heroin, one on heroin and methamphetamine, one on methadone, two on 'poly drug use' and two on non-specific 'illicit drugs'. The research on older adults' illicit drug use has focused predominantly on Class A drugs and mainly injecting as a method of use.

Pope et al. (2010) helped to put initiation of drug use into context by exploring social motivators for a specific group of older users. Anderson & Levy (Anderson & Levy, 2003; Levy & Anderson, 2005) explored lifetime use and changes observed over time in injecting heroin users. This provided an important perspective on the lifetime experience and demonstrated the ways in which the person's sense of self is bound up with their drug use history. Boeri and colleagues (Boeri, 2004; Boeri, Sterk & Elifson, 2006, 2008) aimed to develop a typology or determine defining characteristics of older drug users which helps to understand the within-group similarities and differences of older drug users. The findings of the above research have implications for treatment approaches for older users, which was the focus of two papers (Roe et al., 2010; Smith & Rosen, 2009).

A synthesis of the research is presented below and is structured into three key common findings; isolation and vulnerability, the importance of life history, and drugs and the ageing body.

Isolation and vulnerability.

All of the eight papers on older people's illicit drug use presented findings or data portraying older users as isolated and vulnerable. The isolation is reported to have come about via a number of events or circumstances. The articles present multiple losses for people which may be particularly significant for older people including the death of family and friends, divorce and loss of children, disengagement

with family, and loss or reduced importance of mainstream roles and activities. Levy and Anderson (2005) mapped the 'drug career' of life-long injecting drug users aged over 50 years and conveyed a 'solo career' which reverberates through the other articles. The argument is that in mainstream life, lives are made up of interactions with other people and roles are entwined with the roles of others. However, in a drug world for many people there is an increasing erosion of interactions and ties with others. This begins with mainstream roles such as going to work or being involved with family and progresses until there is limited or no interaction with anyone outside of a drug world, which can include one's own family. Further erosion of connections can occur within the drug world as former friends stop using and distance themselves or friends die. However, as both Roe et al. (2010) and Smith & Rosen (2009) explain, relationships within the drug world can be turbulent, chaotic, stressful and difficult to maintain. Smith and Rosen go on to argue that through numerous negative experiences, older drug users feel that they can trust no-one, resulting in further isolation.

Most of papers reviewed in this section report that older drug users do not form friendships with younger people in the drug world. The reported reasons for this include a lack of trust between people, fear of violence from younger more powerful people, and the lower status of older users so they are of no interest or use to younger people. In this sense older people are more isolated than young people in the drug world but, since the drug world is hidden from mainstream society, these people are potentially more isolated than older people in conventional society.

Older substance users may possibly also be isolated from health and social care services. Of those who were currently receiving treatment (Pope et al., 2010; Roe et al., 2010; Smith & Rosen, 2009) many had a history of connection with health or drug services and reported mixed responses, including claims of experiencing stigma or prejudice at the hands of general healthcare providers such as general practice, dentists, hospitals and social services (Roe et al., 2010). Smith & Rosen (2009) reported participants feeling that drug treatment services were more interested in policing their behaviour than providing help or support, therefore other needs may not be being met. Levy & Anderson's (2005) participants displayed a reluctance to seek help for health problems because, in addition to the fear of stigmatisation and discrimination, they feared coming to the attention of law enforcement agencies.

Authors of the papers reviewed maintain that various types of isolation make older drug users significantly vulnerable. However, aspects of their drug use history may also put them at risk. Boeri et al. (2008) and Roe et al. (2010) described 'early-onset' and 'late onset' users with 'early onset' being beginning drug use before the age of 30 and 'late onset' being after the age of 30 (Boeri et al., 2008). Roe et al. claimed that amongst early onset users, problems arose through an escalation of recreational or experimental use or following a difficult childhood characterised by abuse or the death of a parent, whereas, late onset often followed a negative life event such as divorce or the death of a significant other person or through getting into a relationship with a drug user. Boeri et al. (2008) proposed that there were particular vulnerabilities associated with each group. Whilst early onset users had often learned ways to control or manage their drug use, they had not learned coping mechanisms for stresses other than drug use and therefore were more likely to rely on drug use as a coping mechanism. Also, since the 'harm reduction' message is relatively new and people were less aware of the dangers of sharing injecting equipment, early onset users had more health problems such as hepatitis B and C, HIV and collapsed veins from continued use. Conversely, people who started drug use later in life were at risk in different ways. Since these people often started drug use after starting a family or building a career, these were not factors that could help to prevent use escalating. Also, some social roles associated with older adults were easier to relinquish, for example, grandchildren could be returned to a parent when the person wanted to use. With fewer motivators to manage use, some people felt that their drug use could become out of control and they had no mechanism or experience to draw on to control use when necessary. Whilst early onset users had learned how to operate in two environments, a drug world and a mainstream setting, late onset users had less experience of operating in a drug world and were potentially vulnerable in a dangerous environment. Finally, whilst late onset users had better knowledge of the risks associated with injecting and therefore generally looked after their health better than early onset users, they had less experience and knowledge of what to do if things went wrong.

Prior to the risks previously discussed, Pope et al. (2010) claim that older African Americans were particularly vulnerable to drug use initiation many years ago due to a lack of a positive cultural identity. The authors argue that African Americans have long been portrayed in negative, stereotyped ways in film, television and news

media creating a powerful influence on the participants' behaviour as they struggled to develop a positive self-image. They propose that this was particularly so in years past, making current older adults particularly prone to initiating drug use when they were younger. They also claim that in years past, black residential areas were targeted markets for drug commodities again making African Americans more vulnerable to drug involvement due to the environment in which they lived.

The importance of life history.

A number of beliefs surround drug use in older adults, such as it being unlikely that older drug users exist not least because people 'mature out' of drug use as they age (Ball & Snarr, 1969; Snow, 1973; Winick, 1962). In addition to that reviewed here, other research has dispelled that belief (see for example, Bell & Montoya, 2000; Beynon, 2008) demonstrating that some users continue through into older age. Authors in this review maintain that much is to be gained by exploring the life histories of older drug users. Through reviewing life histories, Boeri and colleagues (Boeri, 2004; Boeri et al., 2006) developed typologies of injecting drug users, demonstrating the heterogeneity of the group. Whilst for some people drug use had become uncontrolled and all other non-drug related social roles were lost to them, others managed to maintain control over use and important social roles, even for people whose drug use was relatively heavy. The authors did not propose this as a static categorisation, but instead demonstrated that people may move in and out of the various types.

Anderson & Levy (2003), Levy & Anderson (2005) and Smith & Rosen (2009) further demonstrate the importance of reviewing a person's life history when planning interventions. Their research demonstrated that many older drug users reflect on and understand their whole life in the context of drug use. Their many negative experiences have long coloured the way they interact with people including holding them at distance and mistrusting them. The authors argue that factors such as these make engaging in drug treatment and envisioning a life without drugs especially difficult for older, life-long users. However, Roe et al. (2010) commented that, through reviewing a life characterised by negative experiences and events, people can reflect on their resilience and survival which can then be utilised in treatment.

Levy & Anderson (2005) identified a difficulty that may need to be taken into account with older drug users. They explain that for some elderly people there is a

desire to remain in a familiar environment and 'age in place' (Lansperry, 2002). For drug users, this may be to remain in a familiar drug world rather than attempt to find a place in a new, conventional world to which they would need to adjust and learn new rules and expectations. This may present a challenge for drug treatment and aftercare services.

Drugs and the ageing body.

The articles reviewed here state that the effects of drug use on an ageing body are harsh which has a number of implications, including that the body is less able to tolerate the drug or withstand the negative effects of withdrawal. Anderson & Levy (2003) and Levy & Anderson (2005) explain that, as the body declines from years of drug use and through natural ageing, older drug users are less able to gain the means to buy drugs. Since they are no longer physically able to use prior means of gaining money, such as robbery, intimidation or sex work the only means left to them are lower status roles or "the worst and lowest desired roles in the drug trade" (Levy & Anderson, 2005: 250). These inevitably also produce the lowest returns, so one of the ways of managing is to try to do without the substance. This often means that older people are more likely to experience withdrawal effects when they are less able to withstand them.

Linked to this is that reportedly in the drug world there is an "emphasis on youth and invincibility" (Anderson & Levy, 2003:768), therefore people with a body in decline are often marginalised and characteristically experience low self-esteem and low self-worth. Roe et al. (2010) concur that older drug users are more likely to experience physical and mental health problems than their non-using counterparts but are less likely to seek help or treatment.

Discussion of the Findings Across Substances

The above review discussed qualitative literature on the experiences of older substance users. The analysis grouped the papers into the type of substance, however, valuable information can be gathered overall for treatment and health promotion initiatives by considering and integrating the findings across the three areas. Whilst the three substance areas may be considered quite different in many ways, important lessons can be learned from reviewing the literature as a whole. The overall findings may help to identify differences between generations and may assist in strengthening

the call for improved screening and specialist substance use services for older people. Also, for the sake of a complete literature review it seems appropriate to synthesise the findings rather than presenting three reviews under one heading.

The key message from the literature appears to be the centrality of the substance use to the person's life and the difficulty or reluctance in considering altering behaviour. Both smokers and alcohol drinkers indicated functions to the substance use which included managing emotions, processes related to the achievement of relaxation and reward, and sharing an activity. These may be attributable to substance users of any age, however, an additional use for older adults may be to manage the effects of an ageing body or other factors associated with ageing such as the possible loss or reduction of contact with people or reduced structure to the day following retirement from work. It may be more difficult for older substance users to refill the possible gap left by stopping substance use since there may be fewer options for older people to create a new or alternative life for themselves. In mainstream society, older people are marginalised (Milne, 2010; Victor, 2005) and there is not an opportunity to start a family or begin a career as there may be for younger people stopping substance use. Particularly in drug treatment, care providers may need to be aware that extra effort may be required to help older people make new meaningful connections outside of the drug world.

National affiliation, cultural identity and gender identity may also be bound up with a person's substance use. Health promotion messages and policy makers need to take this into account since changing one's substance use may challenge or require changing a number of aspects about one's self.

Generational differences may mean that any approaches to treatment which involve group activities may be less effective for older people if the group is primarily comprised of younger people given that the experiences, interests and future outlook may be very different between the younger and older groups.

On the basis of the findings, from a treatment perspective, it could be argued that it would be useful to consider the additional factors that may affect older people as well as substance use, therefore some ways of working that are offered to older people such as reminiscence work and bereavement counselling may be usefully integrated or combined with substance specific interventions. However, these approaches may need to be used with extra care and sensitivity to the context since many older drug users may have experienced a great deal of death and loss.

Limitations

The present review posed a number of challenges. The qualitative literature found as part of the search was varied and given the more recent developments of qualitative methods when compared to quantitative ones, this was to some extent not entirely surprising. The reviewer had two tasks; one was to assess the type and amount of qualitative literature focused on older adults substance use. Simultaneously, the second task was to review qualitative studies focused on the user's perception in order to inform this area, in contrast to quantitative studies that dominate previous reviews and tend to transpose methods and concepts derived from younger populations of substance users. Hence the aim was to understand the key factors, concepts and psychological processes that are specific to this group from the participants' perspectives.

As mentioned, the integration of the range of studies posed some challenges. As an example, looking at non-problem drinkers alongside drug users and smokers who already had a smoking-related illness limited the overall conclusions that could be drawn. For two of the groups it is assumed that the aim would be to stop the use of the substance, however, since the drinkers are not drinking problematically, it is difficult to draw that section into generalised conclusions.

Only one researcher read and assessed all of the research papers. The quality assessment section could have been strengthened by having a second person also assess the articles to provide a degree of inter-rater reliability.

It appears that the literature reviewed is at an early stage of development and studies available are dominated by one-to-one interviewing and adaptations of Grounded Theory methods as an approach to analysis. The field would benefit from a broader range of research utilising alternative theoretical and methodological approaches and novel methods of data collection. Furthermore, it could be argued that methods of integrating findings across qualitative studies are at an early stage of development.

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EMPIRICAL RESEARCH PAPER

"How do I tell my children about what my mum's like?": Conflict and dilemma in experiences of adult family members caring for a problem-drinking parent.

Abstract

Previous research on the effects of alcohol abuse on family members has primarily focused on spouses, parents or young children of problem drinkers. This study explored the experiences of adults with children who were also providing care for a problem-drinking parent. Individual interviews were conducted with six female participants. A qualitative analysis of the interviews identified three conflicts or dilemmas that the participants faced; 'normative notions of family vs. experience', 'emotional detachment vs. strong emotion' and 'functional/practical contact vs. emotional/relational contact'. Implications for alcohol support services are discussed and recommendations are proposed.

Introduction

In the early 1990's Moos, Mertens and Brennan (1993:485) reported that "adults age 55 or older comprise a substantial proportion of substance abuse inpatients" in the USA, with alcohol being the most common substance of abuse (see also Crome & Crome, 2005). Since then, substance misuse has increasingly been perceived as a problem in older adulthood (Dar, 2006; O'Connell, Chin, Cunningham and Lawlor, 2003; Moos, Schutte, Brennan and Moos, 2009), which could be set to rise, with researchers predicting a doubling of the number of older adults in the USA with a substance use disorder by 2020 (Han, Gfroerer, Colliver and Penne, 2009). Closer to home, O'Connell et al.. (2003) warn that "the absolute number of elderly people with alcohol use disorders is on the increase and a real danger exists that a 'silent epidemic' may be evolving" (p. 664). Substance misuse affects not only the individual substance user but also has negative effects on the family. Orford, Copello and colleagues have conducted extensive research on family members affected by a relative's substance misuse and have identified common stresses, strains and methods of coping across families and across cultures (see for example, Orford, et al.., 1998a, 1998b, 1998c; Orford et al.., 2005). However, this research is quite narrow in the range of people studied so far. Female partners and mothers are the family members most represented in research which examines the experiences of the family (Orford et al.., 2005). In the existing body of research literature, 'children' affected by substance misuse are typically young children or adolescents who live with the substance user (Templeton, 2010; Velleman, 2004). Research focusing on adult-children of substance misusers has, thus far, predominantly either taken a retrospective approach exploring memories of childhood, or assessed the later implications of the participants' childhood experiences (see, for example, French, Balsa, & Homer, 2009; Woititz, 2002). Therefore the research base would be strengthened by extending the types of people studied and the research approach adopted.

Caring for Ageing Parents

Many people find themselves fulfilling the role of carer for their ageing parents. Research has been conducted which explores people's motivation to provide care for family members, with filial obligation, (Wallhagen and Yamamoto-Mitani, 2006), attachment (Cicirelli, 1993), reciprocity, (Schwartz et al. 2005), affection or 'friendship' (Stuifbergen and Van Delden, 2011) and perceived need (Oudijk,

Woittiez and de Boer, 2011) figuring strongly as factors for analysis. Whilst there appears to be little agreement about the specific role of key motivators to provide care, there is agreement that caring can often have an emotional impact on the carer leading to feelings of burden, stress and strain (Chambers et al., 2001; Lane et al., 2003). This may be particularly apparent where people are managing competing commitments and responsibilities (Farran, Loukissa, Perraud and Paun, 2004) such as employment or other family commitments. Occupants of the 'sandwich generation' arguably have a double burden of caring for both the previous and the subsequent generation at the same time (Pierret, 2006). Loomis and Booth (1995, p131), however, dismissed as a "myth" the notion that the care burden experienced by the 'sandwich generation' negatively affects carers' well-being. Similarly, Grundy and Henretta (2006) argued that, generally speaking, by the time one's parents are of an age to need care, one's children are older, with a reduced call on one's time and resources. A group of people who may find themselves in a 'double burden' position are people who have a parent who requires attention or support earlier in the offspring's adult life, such as the families considered in the current study. This may compare with the experience of family members caring for an elderly parent with other problems in later life (Maxwell, 2009; Nordmeyer, 2009) including Alzheimer's disease (Werner, Goldstein and Buchbinder, 2010) and dementia (Adams, 2006; Lieberman and Fisher, 1999) whilst they also have a young family to attend to.

Caring for Ageing Parents with a Substance Use Problem

Research on the effects of substance use on families led Copello and colleagues to the identification of a need for a "wider use of family focused interventions in routine practice" for substance misuse (Copello, Velleman, Templeton, 2005, p369) and to the development of a 5-Step Method of intervention to support family members (Copello, Orford, Velleman, Templeton and Krishnan, 2000; Copello, Templeton, Orford and Velleman, 2010). Since alcohol use disorders in older adults are commonly under-recognised by healthcare professionals (Dar, 2006; O'Connell et al., 2003), this suggests that a significant number of families may be attempting to manage an older adult's alcohol problem without sufficient or appropriate support. To date, there is a dearth of research looking at the specific stresses and experiences of adult family members who are caring for an older parent who is experiencing a significant substance misuse problem. The current study aimed

to add to the literature by extending the range of family members studied, including examining the ongoing relationship between the adult child and their parent(s) and exploring multiple inter-generational effects of substance misuse. Qualitative research methods were employed because, through careful use, an analyst can demonstrate a sensitivity to the context (Yardley, 2000), that is, to the detail of the participants' lives and develop an understanding from the participants' perspective (Smith, Flowers & Larkin, 2009).

The principal research question examined in this study was 'What are the experiences of an adult with children who is also providing care or support for their parent who has an alcohol use disorder?

Method

Design

The study used a qualitative design adopting Interpretative Phenomenological Analysis (Smith et al., 2009) as its underpinning approach and methodology. Data were generated via individual semi-structured interviews which were audio-recorded and transcribed verbatim before analysis.

Ethics

Ethical approval for this study was sought and granted by the University of Birmingham and the National Research Ethics Service (NRES) West Midlands Committee of the National Health Service. Although participants were not recruited directly from NHS services, the drug and alcohol charity primarily used for recruitment accepted referrals from the NHS and therefore patients could be potential participants. Documents relating to ethical considerations can be found in the appendices. (See appendix 5 for a letter of sponsorship from the University of Birmingham; appendix 6 for the NRES approval letter; appendix 7 for the advertisement poster; appendix 8 for the Participant Information sheet; appendix 9 for the Consent Form and appendix 10 for the advertisement placed in a carer's group's newsletter).

Recruitment

Interested potential participants were provided with an email address or telephone number to contact the researcher. During the initial conversation the topic

of the study was outlined and the researcher checked potential participant against the inclusion criteria. A number of people were thanked but declined at this point due to reasons such as having no children, the parent had died before the potential participant's children were born or the parent was of working age and still in employment. In cases where the potential participant met the criteria the researcher arranged for the Participant Information to be sent and an interview time and date were agreed. The day before the proposed interview the researcher contacted the potential participants to check that they wanted to go ahead after reading the information and to confirm the day and time of the meeting. Two people dropped out at this point; one due to a family bereavement and the other due to concerns that since he was offered money for travel he may be 'in trouble with his benefits' so he declined to take part.

A potential strength of the recruitment process was that the participants came from a variety of settings and therefore represented a wider group than may be gathered from just one source. However, the recruitment process represents a weakness in the study as discussed further later in the report under 'Limitations of the study'. It was considered that a potential route may be to ask older adults in treatment for permission to approach their offspring, however, this may introduce additional ethical complexities which would need to be considered. Ethical approval would need to be sought to approach the older adult drinker as this was not included in the original application.

Participants

Six participants were recruited to the study. All of the participants were female and had at least one child. The participants' ages ranged from forty to early-sixties. All of the women stated that their parent (or parent-in-law) had been drinking problematically for as long as they could remember, although one (Andrea) could remember some periods in the past when her parent did not drink. Participants who had a parent who was still alive were geographically close to their parent; typically "a couple of miles away" or "just up the road". In relation to ethnicity, all participants were white; four were British and two were Irish. Information about each participant is provided in Table 2.1. Participants have been provided with pseudonyms and any other identifying details have been altered in the transcripts to maintain anonymity.

Table 2.1 Brief details of the participants

Participant	Age of Participant	No. of children	Age(s) of child(ren)	Parent with alcohol problem
Andrea	49	1	14yrs	Mother
Joan	61	5	In 40s and 30s	Mother
Karen	52	2	Both in early 20s	Father-in-Law
Sue	48	1	In 20s	Both parents
Jen	40	2	6yrs & 8mths	Mother
Mel	44	3	13, 11 & 8 yrs	Mother

Participants were recruited from a variety of sources over a five month period. One responded to an advertisement placed in a local drug and alcohol charity where she took her mother who attended an art group. She had previously been a member of Al Anon (a self-help support group for families of problem drinkers) although she had not attended for many years; however, she still had a friend who attended the group. Through contact with that friend, two women contacted the researcher from the local Al Anon group. One participant was known to the researcher who disclosed herself as meeting the inclusion criteria. An advertisement was placed in local carers' groups' newsletters to which one person responded who was involved with the carer group through her role as carer for a different family member, not her parent. She then introduced her sister to the study.

Data Collection

Data were generated via semi-structured one-to-one interviews. These were audio recorded and transcribed verbatim. An interview schedule (see appendix 11) was used to guide the interview rather than to be used as a specific set of questions. The 'semi-structured' nature of the interviews allowed flexibility within the conversations to enable individual stories to be told, whilst maintaining some comparability across interviews. The interview schedule was an adaptation of the Orford et al.. (2005) schedule which covered seven broad areas of interest. Interviews explored participants' perceived stresses, ways of coping, possible tension between generations (ie, tensions between their involvement with their parents and being a parent to their own children) and social support available to the family member.

Participants were asked where they would like the interview to be conducted. A small section of the drug and alcohol charity operated out of some rooms in a local leisure centre and a room was made available for the researcher to use for interviews.

This provided an ideal setting for two of the participants who asked for "neutral ground". Other participants were interviewed within their own home in a private room. No-one else was present at any of the interviews although two of the participants' husbands were in the house, in a different room. Participant information had previously been emailed to the women to read prior to the meeting but a hard copy was also provided and discussed along with the consent form before the interview began.

Method of Analysis

Given the 'experiential' nature of the study, Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) was employed to analyse the data. IPA has two key commitments; "the phenomenological requirement to understand and 'give voice' to the concerns of participants; and the interpretative requirement to contextualize and 'make sense' of these claims and concerns from a psychological perspective." (Larkin, Watts & Clifton, 2006, p102). Transcripts were read a number of times for the analyst to become familiar with the data. Various elements of the texts were noted and selected as possibly important or useful to the analysis; in particular, phrases that concentrated on individual women's experiences or feelings about a topic, rather than generalised statements or facts. Line-by-line coding was performed on each transcript individually (see appendix 12a for an example). Initial codes were drawn together for each participant individually (see appendix 12b). The initial codes were then formulated into themes across the whole data set (see appendix 12c). The themes which appeared to capture the participants experiences were formulated into a model which depicts an interaction between the roles family members play in each other's life, emotions expressed by participants and how these relate to the contact they have with their drinking parent (see figure 2.1). Although the model indicated the relationship between the three factors it did not capture the conflict and dilemmas expressed by the participants, so dynamic themes were developed. Normative notions of parents, parenting and family relationships were detected in the data alongside descriptions of experiences which diverged from normative expectations. Accounts of emotional detachment were evident in interviews which, at the same time, were heavy with emotional content. The analyst observed descriptions of the activities of the relationships, including what people did 'with' or 'for' their parent and their children. These were all highlighted and drawn together to capture the experiences being

conveyed. After writing up the analysis, the findings were sent to the participants for feedback and comment (see appendix 13).

Figure 2.1. A model depicting the interaction of factors within the relationship
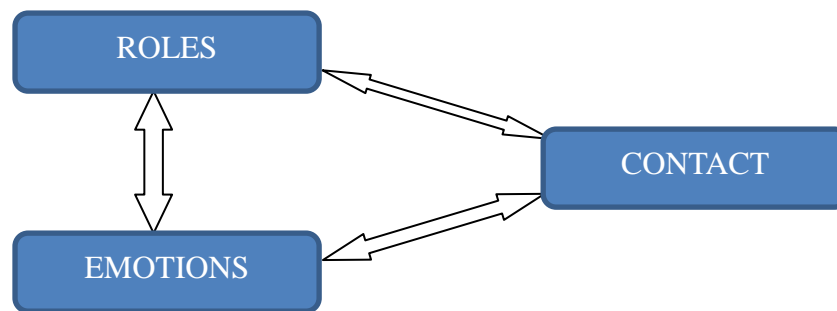
Reflexivity

The researcher in this study had limited experience of the subject matter but was not utterly naive to the area. Whilst having previously conducted research in alcohol misuse, the focus had been on the person with the drink problem rather than family members. Similarly, therapeutic work previously undertaken had been with problem drinkers but never with family members. This project represented a new venture into not entirely unfamiliar territory.

In relation to the participants, the author is an 'outsider' (Langdridge, 2007) in terms of not meeting the study's inclusion criteria. The position adopted by the author towards the families investigated is that promoted by Orford, Copello, Velleman and Templeton (2010). Rather than viewing these families as somehow pathological, dysfunctional of deficient as many models have previously cast them (Orford et al.., 2010) the author positioned the participants as coping in the best way they could with the difficulties they encountered.

In keeping with the IPA epistemological position, rather than viewing the participants words as an accurate, factual record of events and experiences, the interviews were seen as co-constructed accounts between the two speakers creating an understanding of the participants' version and experience of their world.

<center>**Analysis**</center>

A clearly apparent observation throughout the analysis across the transcripts was that participants described feeling "constantly anxious", "weary", "sick of it", and like "I can't be doing with this anymore". Through a close analysis of the accounts provided by participants it appears that their relationship with their parent(s) was fraught with conflicts that became a daily battle which may underlie the emotions they were expressing and characterise their experiences. The following section describes three key conflicts evident in the data and illustrations are provided with extracts from the interviews with longer quotations presented indented. The three themes are 'normative notions of family vs. experience', 'emotional detachment vs. strong emotion' and 'functional/practical contact vs. emotional/relational contact'.

Normative Expectations or Notions of Family Versus Experience

Participant as adult child

Participants talked about 'ordinary' situations and relationships which may be culturally expected or normative. These included aspects of parent/adult-child relationships such as attending weddings, parents visiting their adult daughter in hospital after the birth of a baby, parents listening to the adult-child's problems and offering advice or guidance. Apparent in the interviews were also situations and notions associated with culturally normative grandparent/grandchild relationships such as playing games together, sending birthday cards and 'babysitting' or caring for the grandchild in their parents' absence. However, each of the participants described how their experience was different from expectations and was 'soured' by the older parent's drinking.

Participants spoke about the possibility of their parent being the mother, father or grandparent they would want them to be or could culturally, normatively expect them to be. For example, Joan recalled that "my mam without drink was a loving woman" and others recalled sharing interests or activities with their parent on occasions in the past. However, whilst indicating what may be expected from a loving parent, each provided an account of their own experience. Joan added that…

R: "but erm (.) with drink you got (.) you got belted you got beaten

I: right

R: for the least little thing. She was never any hugs or kisses or

I: right

R: you were never told you were lovely or she loved you"

Each spoke of their parent being "drunk" (Sue) or "paralytic" (Karen) when they visited the new baby in hospital. Jen recounted a conversation with her aunt whom she asked "do you know what it's like your mum not turning up to your wedding because she's pissed and doesn't know what day it is". Each also spoke of their parent not being available to them for emotional support. This also extended to the sober parent where there was one, who became so overwhelmed by the need to attend to their spouse they became less available to their child. This led some participants to feel that they had lost both parents although only one was drinking.

Participants oriented to this being a particular type of relationship with an array of powerful cultural expectations attached to it. They felt in a very different position to others around them who had "a different attachment" (Jen) to the drinker, such as a spouse, sibling or health professional. For some participants this left them feeling isolated and trapped, as Andrea indicated

"A lot of my friends have left drunken husbands but when it's your mum you can't leave your mum, I mean, you can leave but she's always your mum"

The conflict for participants became most acute when the roles reversed and the 'child' becomes the care giver. Cultural expectations of filial caregiving suppose that when the parent becomes elderly or in need, the son or, more usually, the daughter provides care (Hequembourg & Brallier, 2005). However, the participants indicate a lack of reciprocity and point to a troubled relationship and history. This is most clearly vocalised by Jen

"I don't think people, service providers understand. It's like my auntie will say to me 'oh it's like she's got dementia' but I think 'ok if I'd had a relationship with my mum and then she'd got dementia I wouldn't turn away from her because I would want to care for her' but that's not what's happened. We've had an ongoing from childhood errm volatile and unloving relationship and then all of a sudden someone's telling me to care for her and they don't

understand what emotion is attached to that and you just think that lack of understanding about that, about the illness or the alcoholism whatever you call it and what you expect a family to do is not realistic I don't think and that's why I think- I don't think people should expect that a family member can care for somebody with alcoholism like they would expect someone to care for an elderly relative or someone with dementia because I think it's very different"

The conflict or dilemma participants appeared to find themselves in and described involved feeling trapped in a relationship that has not been nurturing or positive and feeling the burden of expectation that they should now provide care. It appears that whilst their experience negatively contrasted with normative notions of parental care, they were trapped into normative notions of filial caregiving in later life.

Participant as parent

Similar to descriptions of possible parent/child relationships in their past, participants' accounts indicated what sorts of things may constitute a 'normal' grandparent/grandchild relationship. However, again reminiscent of their past, this was not their child's experience. This gave rise to further conflicts experienced by the participants. Firstly the participants felt that they wanted their child to have a relationship with their grandparent, and in many ways the grandparent was, at times, able to fulfil the relationship to the satisfaction of the child. Andrea recalled her son when he was young excitedly asking "shall we go to granny's, shall we go to granny's" while Sue confirmed of her parents and her son "they loved him. And he loved both of them". Karen recalled that her father-in-law "was very good with the children he loved the kids" and "used to play with them and you know talk to them and stuff" and this was echoed in other participants' stories who talked of children who enjoyed spending time with their grandparent. However, Karen went on to portray a contrast between a 'good grandad' and an 'unsafe grandad' with whom she did not feel she could entrust the children's care. Similarly others talked about the relationship becoming damaged because the grandparent was "really mean to them", "really nasty", "embarrassing", "unpredictable" and "aggressive" leading the participant to question the child's physical and emotional safety. Mel explained that "what I've had to say is 'oh Nanny Smith's got some problems'" to account to her

children for her mother's "nasty" behaviour, whilst Andrea's son's relationship with his grandmother has deteriorated to such a degree that "he doesn't really talk to her anymore".

As indicated earlier, participants felt tied into or trapped in the relationship with their parent and, at the same time, they did not want their child to be affected by their own parent's drinking in a way that they recall being affected themselves by it. Subsequently, participants talked about going to some lengths to "protect" and "shield" their children from their drinking parent's behaviour. Speaking of her son Andrea stated

> "we try and protect him quite a lot from it. He's never seen her really drunk because I don't see why he should … why put your child through that"

They also indicated changes in their relationship with their parent when they had a child of their own due to the desire to protect their offspring, adding a further layer of complexity to an already difficult relationship.

> "then it was very different because I had someone to protect, I had someone to stand up for other than me so it was very different and I think having children has really changed my attitude, my tolerance levels to do with my mum" (Jen)

Emotional Detachment Versus Strong Emotion

The interviews with adult children of problem drinkers in this study were laden with emotion. This was evident from the direct expressions of feelings and the indirect 'cracking' or 'wobbling' of voices, occasional welling of tears in participants' eyes and muscles taut with emotion. At the same time, each talked about emotionally detaching themselves from their drinking parent. Each spoke of it as a coping strategy to manage their own reactions and protect themselves and their family from hurt.

Participants talked about a lifetime of trying to stop their parent from drinking and hoping that it would be possible. Each spoke about hoping that the birth of their child would prompt their parent to stop drinking, however, each also indicated the painful emotions they felt when this did not happen. In response to the question "so when your son came along how did that change things with your parents. Did it change the relationship with them?" Sue visibly fought back tears as she replied in a broken, 'wobbly voice' "no it didn't change anything" and reiterated later "having the child didn't make it better" with a sound of painful resignation.

The discovery that a new family member and, more importantly, *their* offspring would not prompt a change in drinking behaviour was a double blow for some, rubbing new 'salt' into old 'wounds'. Participants talked about feeling that their parent had chosen alcohol over them when they were young and again now with their own child they were "rejected again" (Joan). This fuelled their desire to protect their own children and they did not want their child to experience that 'rejection' as Jen affirmed

"we felt like we were being rejected. It was a feeling that she was making the choice of alcohol above us when for me I didn't want her to do that over my children so I didn't want her to reject my children because of alcohol"

A whole gamut of emotions was conveyed, including "shame", "fear", "anxiety" and "hurt". "Anger" and "resentment" were expressed towards the parent for their behaviour, a sibling for leaving and not helping with the parent or health professionals for being unsupportive or placing unrealistic expectations on the family. Andrea declared

"that's why I'm so resentful thinking 'how can you do that to your child'. I know I'm a grown up with their grandson but you just think 'how can you do it'"

Whilst Jen recalled a conversation with her mother's GP

"She (the GP) said something like 'well it's those times when she's finding it hard when she wants to drink that she needs you most' and I'm saying 'well those are the times when we can't cope the most'"

In order to avoid being hurt, participants talked about emotionally detaching themselves from their drinking parent. Mel explained that "you just don't want to go through that emotional strain" while Sue concurred "I suppose I was protecting myself, I just put up a big barrier between us". These sentiments were echoed by Andrea who stated that "I'm not really interested in having a relationship with her because it's too hurtful". For Jen this was a process over time. She recalled

"my mum was hugging me and saying 'oh I'm so sorry for anything I might have done' and she was crying and I know that I was going 'oh don't worry about it mum' but I know when I was patting her and cuddling her and saying 'don't worry about it mum' I was really thinking in my head 'I don't give a

shit' that's what I was thinking in my head and that was a very new kind of feeling and I suppose every time I had these new kind of feelings I recognise it was very different to the emotions I used to feel. I thought 'I don't give a crap if you're upset really' is what I was starting to feel"

The dilemma or conflict for participants here appeared to be how to protect themselves and their child(ren) by emotionally detaching themselves from a person or situation that arouses very strong emotions in them.

Functional/Practical Contact Versus Emotional/Relational Contact

Participants described the contact and interaction they had with their parent. These interactions appeared to be bound up with the roles each played in the other's life and featured ways to manage emotions.

Participants expressed being caught up in a relationship which for them was emotionally painful with a parent who was emotionally unavailable to them. In order to manage this, the relationships appear to have become increasingly functional or practical, such that, the contact served a particular purpose. This may be to resolve a practical problem experienced by the older parent, to support a sober parent or to ease their own feelings of guilt about attempting to emotionally detach. Jen illustrated features of the conflict in the following extract

J: "Mick (Jen's husband) was saying 'I just don't know why you put up with it, I just don't know why you put up with it. I think you should not have anything to do with her' and me saying 'yeah but she's my mum, I can't just not have anything to do with her' especially when it came to times like her heating broke down in the middle of the winter and the things errm that we'd go to her rescue or she'd go in to hospital so she needed someone for her when she was in hospital and these types of things really errm so she would phone us when she needed some help or she would phone us when she'd had a drink and wanted to talk or cry down the phone to us about the latest story line in Coronation Street

Int: right right

J: and that used to really irk me because she had more emotion about what's happening in the soap operas on telly than she would about what's going on in her own family's lives"

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Jen indicated the feeling of not being able to end the relationship by stating that "I can't just not have anything to do with her" and listed the types of situations that would see her going to her mother's aid. She then intimated the sorts of emotional requests that her mother made of her but then demonstrated her mother's lack of emotional reciprocity by having "more emotion" about events in a soap opera than her own family.

Sometimes 'rules' were placed around the contact, for example, the parent would have to be sober at the time the participant helped to resolve the problem. However, this often resulted in more hurt when the parent reportedly failed to keep their end of the deal or drank again as soon as the need had been met. The longevity of the difficult relationship and the hopelessness associated with it are captured by Andrea

> "We've sort of come a long way to get to where we are today and we've been
> through all different things of trying to love her or trying to be hard to her and
> all this sort of stuff and nothing makes any difference really"

Participants expressed that their involvement with their parent was now more about obligation and duty rather through choice or pleasure

> "there really isn't a relationship at all now, I just have to look at her. I only
> have contact with her for my dad now… I wouldn't have contact with her for
> any other reason" (Andrea)

> "now I am seeing her just because I feel guilty … I just feel like it's more of a
> duty really" (Mel)

The fall-out of the previous two conflicts, as described above in this analysis, appears to be played out in the contact the participants had with their parent. The conflict faced here centred on balancing a relationship that is influenced by the roles, responsibilities and expectations of each of the actors in the relationship and the emotions experienced by the participants. A relationship embracing cultural notions of 'family' and supportive relationships which include shared emotions may move contact towards an emotional or relational interaction. However, tense, unpredictable or difficult relationships with emotional disengagement may tip the contact towards a functional or practical interaction. Participants appeared to be in a state of flux about aspects of their relationship and contact with their parent.

Participant Feedback

A summary of the report (see Appendix 13) was emailed to the participants who were asked to provide comments and feedback. Two replied, saying...

Andrea – "The only comment I would add is the pressure of the other parent with regards to supporting them whilst they are caring for the alcoholic. For myself that is more difficult in some ways than the drinker- but maybe that's just my situation."

Jen – "I do recognize most of what is included, of course some is not relevant to my experience. It does sum up my experience though it's strange to read about it as it doesn't show the emotion I feel when I talk about it."

Qualitative research aims to capture common features and create a general understanding of the participants' experience; therefore it cannot sum-up exactly the situation of each individual. The two respondents indicated that the analysis in this study identified the shared phenomena sufficient for them to largely recognise their experiences within it. This adds to the validity of the research.

Discussion

Close analysis of qualitative interviews with adult parents who cared for their own parent who had a significant drink problem identified a number of daily conflicts or dilemmas faced by participants and at the centre of the relationship with the drinking parent. The overall picture was one of contrasts between perceptions of 'normality' and the reality of fragmented relationships. First was a contrast between what the affected family member perceived as being 'normal', 'ordinary' family experiences and relationships, which was then contrasted with much of what the participants experienced which they indicated was poor in comparison. The conflict for the speakers was related to the burden of filial caregiving that they felt was placed on them when they themselves perceived that they had not received parental caregiving as a result of the impact of the alcohol problem on their own parent and in turn his or her parenting towards the participant. Secondly, participants spoke about emotionally disengaging from their drinking parent as a means of protecting themselves from further emotional hurt. However, participants indicated that this was very difficult in a relationship which roused deep, strong emotions and, indeed, the

process of separating from the parent provoked feelings of guilt and further discomfort. The third conflict centred on the contact between the parent and adult child. Whilst at some point an emotional or relational contact may have been desired by either or both parties, the impact that each family member had on the other's life and the emotions attached to the relationship rendered this too difficult and emotionally painful. Participants therefore attempted to move towards a practical or functional focus for the contact devoid of emotion which proved difficult to maintain. The overall picture is one of fragmented relationships (Adams, 2008) where the impact of the substance misuse leads to fragmented intimacies for those with the problem as well as those family members affected by the substance misuse.

The findings of this study resonated with previous work on adult family members of a person with a substance use disorder. Orford, Velleman, Copello, Templeton and Ibanga (2010) concluded that, although essentially the experience of family members is universal, it is coloured by the particulars of the relationship and characteristics of the people in it. Also, overall, the picture portrayed in this study is one of detachment and disengagement over time whereby the family member finds a position of emotional distance the longer the problem continues. This conclusion was also drawn by Copello (2003) with other family members of people with a substance use problem.

Significant for this group of family members is the intergenerational position they occupy, caught between managing their parent and protecting their child(ren). Similar to findings with other family members affected by substance misuse problems, participants reported a persistent feeling of unpredictability and uncertainty about what may happen at any time in relation to the drinking parent (Orford et al.. 2010). Significantly, these participants indicated feeling trapped in a situation perceived to be not of their own making but with no means of escape. This was reportedly because participants felt obligated to provide support for the drinker because there was a perceived need and if they did not provide support they reported fearing that there was no-one else to provide it, or in addition, because a sober parent (the other, non-substance using parent) required their help and support.

Previous research indicated that factors that motivate people to care for an ill or frail elderly parent include filial obligation, (Wallhagen and Yamamoto-Mitani, 2006), perceived need (Oudijk, Woittiez and de Boer, 2011), attachment (Cicirelli, 1993), reciprocity, (Schwartz et al.. 2005) and affection or 'friendship' (Stuifbergen

and Van Delden, 2011); however, amongst the group in this study there was a distinct absence of references to attachment, reciprocity and affection or 'friendship' in the relationship. Since care based on these latter factors appears to mitigate feelings of burden and stress (del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011; Reid, Moss & Hyman, 2005) whilst increased feelings of obligation have been found to be associated with increased subjective burden (Cicirelli, 1993), this has obvious implications for the well-being of the people in the position of those in this study. There were several references in the descriptions of participants to the experience of stress related psychological and physical symptoms, a consistent finding in the literature on family members affected by substance misuse problems (Ray, Mertens & Weisner, 2007; 2009). Research indicates that, although adult-children can find caring for their parent tiring and stressful, there are rewards to be gained including feeling like one is giving back to a parent who cared for them when they were young (Lane et al.., 2003). This aspect however, appears to be absent from the accounts of the participants in this study and there is little evidence of pleasure in the descriptions of current relationships. This suggests that further support for adults managing a parent with a substance use disorder is required in order to achieve a more balanced position in the relationship and leads to some recommendations outlined in the final section of this report.

Limitations of the Study

The study design was based on qualitative methods given the emphasis and aim of attempting to understand the lived experience of the type of adult family members that were involved in this research. The usual limitations of the extent to which qualitative findings can be generalised apply; however, the present study was more concerned with an initial exploration of a group that to date has been largely neglected in research into family members affected by addiction problems. As such it provides the first findings specifically focused on this group and highlights some of the specific potential additional sources of stress associated with the conflicting roles and responsibilities of those positioned between two generations (Grundy & Henretta, 2006; Pierret, 2006).

A further limitation is the extent to which conflicts and difficulties in the adult and parent relationship may be part of the general psychology of these interactions and not necessarily related to the impact of the addiction problem but potentially

arising from other factors. The important issue here is the fact that in the participants' views, these problems were attributed to the impact of the substance related problem and as such, an understanding of these attributions may be important to address within interventions to support these family members.

Clinical Recommendations

An implication of under-recognition of substance use problems in older people suggests that there are likely to be families struggling to cope. Better identification of substance use problems in older adults may provide an opportunity for support for these family members which may have positive multi-generational effects and outcomes. However, this support needs to be timely and delivered as early as possible in the relative's substance abuse career. Results of this study indicate that many people cope with their situation by emotionally disengaging and keeping aspects of their drinking parent out of their home life, but to seek support for themselves may be experienced as investing more time, energy and thought into the relationship, therefore the benefits for the adult-child and their own family need to be very clear.

In addition to adult family members, this study implies that it is important to provide a service to children affected by a parent's drinking to help them as they become adults. Templeton (2010) outlined a method of working with affected family members which could be adapted to be appropriate for young children. Further adaptations could be undertaken with a more specific focus on the group of adult family members concerned about an older parent that have been the focus of this study.

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EXECUTIVE SUMMARY

Literature Review.
Older adults' experiences of substance use: a systematic narrative review of qualitative literature

Background

The number of older adults with a substance use disorder (SUD) has been increasing over recent years and is set to continue rising. Research has suggested that older adults may be able to benefit from treatment for SUDs, however, interventions and health promotion initiatives have not been developed for older substance users. In developing such programmes it is imperative that the service users perspective is taken into account, yet, to date, no review has been conducted which captures the views of older substance users.

Aim

The review set out to advance an understanding of the experience of older substance users and the meaning of substance use for older adults. It was anticipated that differences between older and younger adult substance users reported in the research would be highlighted.

Method

Qualitative research typically aims to capture the participants' perspective and versions of their world, hence, this review employed a qualitative methodology to examine qualitative research. Fifteen research articles published before January 2013 were collected for review.

Findings

After providing an overview of the participant demographics and an assessment of the methodologies employed in the research, the review was organised around three substances; tobacco, alcohol and illicit drugs.

Conclusion

Findings suggest that substance use is central to the older adult's life and altering their behaviour may involve challenging or changing aspects of themselves. Furthermore, the culture and context of substance use among older adults display some features specific to this age group indicating a need to understand this group separately from younger users.

Recommendations are made for treatment programmes, for health initiatives and for future research.

Empirical Research Paper.

"How do I tell my children about what my mum's like?": Conflict and dilemma in experiences of adult family members caring for a problem-drinking parent.

Background

Many people find themselves fulfilling the role of carer for their ageing parents. This can often be a difficult situation, especially when the caregiver has other commitments such as a young family of their own.

Research indicates that substance misuse amongst older adults is increasing, however alcohol use disorders in older adults are commonly under-recognised or misdiagnosed by healthcare professionals. Substance misuse in the family affects all of the family members.

As these two factors may indicate, the combined circumstance of caring for an older parent with a substance use problem could be expected to be stressful, but since it is often missed by healthcare or support services this suggests that a significant number of families may be attempting to manage an older adult's alcohol problem without sufficient or appropriate support.

Aim

The study explored the on-going relationship between adults and their parents and the ways in which substance misuse problems impact on the relationship. The main aim was to understand the experiences of an adult with children who was also providing care or support for their parent who has an alcohol use problem. It was

anticipated that this would help to discover what particular stressors may be experienced by this group of people.

Method

Participants were recruited via a number of methods including advertising in alcohol services and carer's groups and through participants introducing their friends or siblings to the study. A one-to-one interview was conducted with six women who had at least one child and cared for their parent who had an alcohol problem. The interviews were audio-recorded and analysed for similarities across the interviews. The analysis concentrated on the women's feelings and experiences rather than generalised statements or facts.

Findings

The findings indicated that the participants appeared to face a number of conflicts or dilemmas in relation to their relationship with their parent. Three themes were described in detail in the report which highlighted conflicts related to 'normative notions of family versus experience', 'emotional detachment versus strong emotion' and 'functional/practical contact versus emotional/relational contact'.

Conclusion

The experiences of adult family members caring for a problem-drinking parent appeared to be largely similar to those of other family members affected by a relative's substance abuse, however, the participants and their parent's particular type of relationship brought about a number of contrasts. The specific conditions of this situation also indicated differences between the participants in this study and family members providing support to an elderly parent with older-age-related difficulties

The findings reaffirmed the need for support for family members of people with a substance use problem and indicated that the support needed to be timely, and delivered as early as possible in the relative's substance abuse career.

Instructions for Authors

Note to Authors:** please make sure your contact address information is clearly visible on the **outside** of all packages you are sending to Editors.

Aims and Scope:
For over 40 years, *Substance Use & Misuse (formerly The International Journal of the Addictions)* has provided a unique *international multidisciplinary* environment for the exchange of facts, theories, viewpoints, and unresolved issues concerning substance use, misuse (licit and illicit drugs, alcohol, nicotine, and caffeine), "abuse," dependency, eating disorders, and gambling.

Manuscript submissions must include:

All papers should be submitted online - http://mc.manuscriptcentral.com/lsum. Hardcopies are not permitted. Text files should be submitted as Microsoft Word files. All tables and figures should be submitted as separate individual digital files.

Substance Use and Misuse conducts a double-blinded review process. Authors should be sure *NOT* to include any identifying information in the body of their work (including tables and figures). All identifying information will be asked for during the submission process and will be kept confidential. Any manuscripts containing identifying information will be returned to the Authors.

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides.

Number manuscript pages consecutively throughout the paper.

Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces.

A list of 5-10 key words must also accompany the manuscript, as well as a glossary, containing a list of brief scientific definitions of key terms and concepts.

Each article should be summarized in an abstract of not more than 100 words, containing the following information: year of data collection, brief description of the sample as well as the total N, brief description of the area (country, urban, etc.), instruments used for data collection and the data analysis techniques, whether the study's implications and limitations are noted and whether future research is suggested, and source of funding for the study.

Avoid abbreviations, diagrams, and reference to the text in the abstract.

Appendix 1: Instructions to Authors. Substance Use & Misuse

All ACCEPTED manuscripts are required to provide:

Foreign language abstracts in French and Spanish

A photograph and short biography of each contributing author

Footnotes
Use sparingly if at all. Number all text footnotes consecutively throughout the manuscript and compile them on a separate page at the end of the manuscript.

References
Cite in the text by author and date (Smith, 1983).

Prepare reference list in accordance with the APA Publication Manual, 4th ed.
Examples:

Journal: Vik, P.W., Culbertson, K.A., Sellers, K. (2000). Readiness to change drinking among heavy drinking college students. *Journal of Studies on Alcohol* 44:429-437.

Book: Miller, W.R., Rollnick, S. (1991). Motivational interviewing. *Preparing People to Change Addictive Behavior*. New York: The Guilford Press.

Contribution to a Book: Donovan, D.M. (1998). Continuing care: promoting the maintenance of change. In: Miller, W.R., Heather, N., eds. *Treating Addictive Behaviors*. 2nd ed. New York: Plenum Press.

Web Source: Lynch, T. (1996). *DS9 trials and tribble-ations review*. Retrieved October 8, 1997, from Psi Phi: Bradley's Science Fiction Club. Web site: http://www.bradley.edu/ campusorg/psiphi/DS9/ ep/503r.html
Mershon, D.H. (1998, November-December). Star trek on the brain: Alien minds, human minds. *American Scientist*, 86, 585. Retrieved July 29, 1999, from Expanded Academic ASAP database.

Illustrations
Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be submitted as separate digital files following these guidelines:

300 dpi or higher
Sized to fit on journal page
EPS, TIFF, or PSD format only
Submitted as separate files, not embedded in text files

Color illustrations will be considered for publication; however, the author will be required to bear the full cost involved in their printing and publication. The charge for the first page with color is $1000.00. The next three pages with color are $500.00 each. A custom quote will be

Color illustrations will be considered for publication; however, the author will be required to bear the full cost involved in their printing and publication. A quote will be provided for color art. Good-quality color prints should be provided in their final size. Figures submitted in color will appear online in color, free of charge. The publisher has the right to refuse publication of color prints deemed unacceptable.

Tables and Figures

Tables and figures (illustrations) should not be embedded in the text, but should be included as separate files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet. All original figures should be clearly marked in pencil on the reverse side with the number, author's name, and top edge indicated.

Proofs

Page proofs are sent to the designated corresponding author. They must be carefully checked and returned within 48 hours of receipt. Please note that in the proof stage, only typographical errors, printer's errors and errors of scientific fact can be corrected. No substantial author's changes will be made.

Reprints

Each corresponding author of the article will receive a complete copy of the issue in which the article appears. Reprints of an individual article are available for order at the time authors review page proofs.

It is the policy of all Informa Healthcare to adhere in principle to the Conflict of Interest policy recommended by the International Committee of Medical Journal Editors (ICMJE). (http://www.icmje.org/index.html#conflict)

Appendix 2: Literature search strategy

Literature Search Strategy
The search strategy employed is illustrated below:

First search – (1) 'older adults' = 22821 articles

Second search – (2) substance (drug abuse or drug usage or alcohol abuse or drug dependency) = 122542articles

Third search – (1 + 2) to reduce to articles which appeared in both previous searches = 751 articles

Fourth search – Limit by English language, qualitative study, peer-reviewed journal = 24 articles

Research Quality Assessment Criteria
Considerations in assessing the adequacy of research reports.

The following considerations cover both clarity and sufficiency as standards:
1. The clarity of the writing
      a. Consistency of terms used
      b. Are definitions provided where necessary?
      c. Are sentences sufficiently well constructed to be intelligible and
          unambiguous?
      d. Is there use of inappropriate rhetoric?

2. The problem or question being addressed:
      a. Is this clearly outlined?
      b. Is sufficient rationale provided for its significance?

3. The formulation of the main claims:
      a. Are these made sufficiently clear and unambiguous?
      b. Are the relations with subordinate claims (including evidence) made
          sufficiently explicit?
      c. Is the character of each claim (as description, explanation, theory,
          evaluation or prescription) indicated?

4. The formulation of the conclusions:
      a. Is there a distinction between main claims about the cases studied and
          general conclusions?
      b. Is the basis for the conclusions signalled?

5. The account of the research process and of the researcher:
      a. Is there sufficient, and not too much, information about the research
          process?
      b. Is there sufficient, and not too much, information about the researcher? (In
          other words, is what is necessary and no more provided for assessing
          the validity of the findings, the value of the methods, the competence
          of the researcher, according to what is appropriate?)

Considerations in assessing the significance of research findings.

As regards validity, the following considerations might be involved:
1. The main claims and evidence:
      a. Are the main claims plausible or creditable enough to be accepted at face
          value?
      b. If not, is evidence provided?
      c. If so, is the evidence sufficient, both in terms of strongly implying the
          validity of the main knowledge claim and in being sufficiently
          plausible or creditable to be accepted?
      d. If not, is a further layer of evidence provided?
      e. If so, is this evidence sufficient? And so on.

Appendix 3: Research quality assessment criteria

2. The relationship between the findings about the cases studied and the conclusions drawn:
>   a. Where these are empirical generalisations about some finite population, on the basis of whatever evidence is provided, are they sufficiently plausible of creditable to be accepted?
>   b. Where they are theoretical statements of a conditional causal kind, on the basis of the evidence provided are they sufficiently plausible or creditable to be accepted?

In relation to relevance, the considerations might be:
1. *The importance of the topic*: the research must relate (directly or indirectly) to an issue of importance to the intended audience, or to some potential audience.
2. *The contribution of the conclusions to existing knowledge*: the research findings must add something to our knowledge of the issue to which they relate. Research that merely confirms what is already beyond reasonable doubt makes no contribution (though research which corroborates what was previously suspected but not known with confidence *is* of value.)

In these terms, research findings may connect with an important topic but still not be relevant since they do not tell us anything new about it. Conversely, research may add new knowledge, but this may relate to no topic of any importance and so still lack relevance. Importance and contribution are necessary and jointly sufficient conditions for relevance.

(Hammersley, 2008:162-163)

Appendix 4: Instructions for authors: Families, Relationships and Societies

Appendix 4: Instructions for authors: Families, Relationships and Societies

Appendix 5: Letter of Sponsorship from University of Birmingham

UNIVERSITY OF
BIRMINGHAM

Finance Office

Director of Finance
Mrs G Ball FCCA

Dr Mandi Hodges
School of Psychology
College of Life and Environmental Sciences
University of Birmingham

2nd August 2012

Dear Dr Hodges

Study title: Experiences of adult family members caring for a problem-drinking parent
Sponsor reference: RG_12-030
UoB Ethics reference: ERN_12-0186
NRES REC reference: 12/WM/0178

I am writing to you with regards to the arrangements for the above project, in which you are the Chief Investigator and your Academic Supervisor is Professor Alex Copello. This project is classed as *a Doctoral Student Research Project* and as such comes under the Department of Health Research Governance Framework for Health and Social Care (RGF).

I confirm that the University of Birmingham has agreed to take on the role of Sponsor under the RGF for this research project.

As regards the provision of compensation in the event of harm to research participants in the UK, the University of Birmingham has in force an insurance policy that provides cover for claims for negligent harm in the UK and the research project above captioned is included within this coverage subject to the policy's limits, terms and conditions.

No provision has been made for indemnity in the event of a claim for non-negligent harm to research participants for this research.

It is your responsibility to deliver the research project as described in the research proposal, in accordance with the University's policies and Code of Conduct, the Research Governance Framework and the conditions of the ethics approval issued by the NRES REC.

Please ensure that all data and documentation are available for the purposes of monitoring, inspection or audit by University officers or a third party designated to audit projects on behalf of the University. This includes participant consent forms and information sheets.

Please note that this letter to commence is provisional on obtaining Research Management and Governance permission from the relevant Trust R&D Department where applicable.

RG_12-030 Conf ltr to CI 02-08-2012

University of Birmingham Edgbaston Birmingham B15 2TT United Kingdom

INVESTOR IN PEOPLE

Appendix 6: Ethical approval letter from NHS National Research Ethics Service (NRES) Committee West Midlands

NHS
Health Research Authority

National Research Ethics Service
NRES Committee West Midlands - The Black Country
HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ
Telephone: 0161 625 7832

05 July 2012

Dr Mandi Hodges
Trainee Clinical Psychologist
Black Country Partnership NHS Foundation Trust
University of Birmingham
School of Clinical Psychology
Edgbaston, Birmingham
B15 2TT

Dear Dr Hodges

Study title:	**Experiences of adult family members caring for problem-drinking parents**
REC reference:	**12/WM/0178**

The Research Ethics Committee reviewed the above application at the meeting held on 02 July 2012. Thank you for attending to discuss the study.

Ethical opinion
The Committee welcomed you to the meeting and thanked you for the application.

The Committee explained that they recognised that the research would be valuable and asked about the older adults to be involved in the study. The Committee queried if these adults would have an emerging problem with drugs or alcohol or if they would have had an ongoing problem. You explained that you had given much consideration to this issue. You also felt that there is a big difference between a parent with substance misuse who is on their own and a parent who has a partner. You emphasised that they are looking at the support needs of these adults and as these are not yet known both groups would be included.

The Committee were aware that IPA would be used and asked for further information on this aspect of the study. You explained that they are interested in the experiences of participants so they have chosen this method above others. They would use IPA to help gain a clearer understanding of participants' circumstances including their support needs. They would be looking to find out what was useful or helpful to participants.

The Committee asked if you had experience with IPA of if you had chosen the method for other reasons. You explained that your background was not in IPA but it was the most appropriate method for this study.

Appendix 6: Ethical approval letter from NHS National Research Ethics Service (NRES) Committee West Midlands

The Committee complimented you on the quality of the Participant Information Sheet.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the study.
Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.
Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.
Sponsors are not required to notify the Committee of approvals from host organisations

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

Approved documents
The documents reviewed and approved at the meeting were:

Document	Version	Date
REC application: 96201/329534/1/465		01 June 2012
Protocol	1	01 June 2012
Investigator CV: Mandi Hodges		
Investigator CV: Alexandre Georges Copello		
Participant Information Sheet	1	01 June 2012
Participant Consent Form	1	01 June 2012
Advertisement	1	01 June 2012
Evidence of insurance or indemnity from University of Birmingham		08 July 2011
Letter from Sponsor from Brendan Laverty		08 March 2012
Interview Schedules/Topic Guides	2	01 June 2012
Referees or other scientific critique report: Assessors Marking Sheet		23 September 2011

Membership of the Committee
The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

Appendix 6: Ethical approval letter from NHS National Research Ethics Service (NRES) Committee West Midlands

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

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

Notifying substantial amendments

Adding new sites and investigators

Notification of serious breaches of the protocol

Progress and safety reports

Notifying the end of the study

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

Feedback
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
Further information is available at National Research Ethics Service website > After Review

12/WM/0178   **Please quote this number on all correspondence**

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

On behalf of
Dr Jeff Neilson
Chair

Email: helen.penistone@northwest.nhs.uk

Are you an adult who has concerns about your parent's drinking?

Do you have children of your own?

We are interested in the experiences of people who are caring for a problem-drinking parent whilst bringing up their own family.

We would like to understand how we can help and support you.

If you may be willing to take part in our research study, please ask the receptionist or your support worker for more information

We can reimburse your expenses up to the value of £15

Appendix 7: Advertisement Poster

UNIVERSITY*OF*
BIRMINGHAM

PARTICIPANT INFORMATION SHEET

'You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Title of Project: Experiences of adult family members caring for a problem-drinking parent

Researcher: Dr. Mandi Hodges

I am Mandi Hodges of Birmingham University and the NHS (BCPFT) and I am a Trainee Clinical Psychologist. I have a long-standing interest in substance misuse, particularly alcohol abuse, and have previously conducted research in this area. My current research extends to explore the experiences of family members of people with a substance use disorder.

- **What is the purpose of this research?**
This research aims to explore the experiences of adult family members who provide care or support to their parent(s) who has/have an alcohol problem. Of particular interest is how people manage the competing commitments of caring for a parent and looking after their own family.

- **Why have I been invited to take part?**
You have been invited to take part because we are looking for people who:
  ➢ have a parent with an alcohol use disorder who is 60+ years of age (i.e., the drinking parent is 60+ years of age)
  ➢ consider themselves to have regular contact with the drinking parent.
  ➢ feel that they are significantly affected by their parent's alcohol misuse
  ➢ are living with and caring for, or responsible for, children

- **What will happen to me if I agree to take part?**
You will be asked to take part in a one-to-one interview with the researcher. It is expected to last for approximately one hour and will be audio-recorded. It will take place at a time and date to suit you, either at the Aquarius office or at Birmingham University, whichever is more convenient for you.

- **What will happen if I do not want to carry on with the study?**
During the interview you can pause the recording at any time if you would like a short break. If you no longer wish to take part in the interview you can leave it at any time and any recording will be deleted. Once the interview has finished you could still withdraw your consent to participate within the following

seven days and the audio-recording will be deleted. You do not have to give a reason for your withdrawal, and any support or services you receive will not be affected either by your participation in, or withdrawal from the study.

- **Expenses and payments**

Expenses up to the value of £15 will be reimbursed.

- **What will happen to the results of the research study?**

It is anticipated that the findings of the study will be written up for publication in a peer-reviewed journal and presented at international conferences. All results will be anonymised and it will not be possible to identify an individual participant's real identity.

- **What happens if I have any further concerns?**

Please contact the research team (contact details below) or speak to a member of Aquarius staff as soon as possible.

If you would like to discuss any aspect of this research please contact:

Dr. Mandi Hodges	Prof. Alex Copello
(Chief Investigator)	(Principal Investigator)
Trainee Clinical Psychologist	Professor of Addiction Research

Tel: 0121 414 7124   0121 414 7414

Email: rmh033@bham.ac.uk   a.g.copello@bham.ac.uk

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

UNIVERSITYOF
BIRMINGHAM

Participant Identification Number:...............

CONSENT FORM

Title of Project: Experiences of adult family members caring for a problem-drinking parent
Researcher: Mandi Hodges

Please tick each box

1. I confirm that I have understood the information sheet dated 1-6-12 (version 1) 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 family members' 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 a seven-day period for reflection during which I may withdraw my interview entirely or in part, without giving any reason, without my own or my family member'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 direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.

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

....
Name of participant   Date   Signature

....
Name of researcher   Date   Signature

Carers of people with alcohol problems wanted to take part in research
Dr. Mandi Hodges, a Clinical Psychologist in Training is seeking adults who are caring for a parent (or parents) who have a problem with alcohol to take part in a piece of research. Participants also need to have children of their own. Of particular interest to the researchers is how people manage the competing commitments of caring for a parent with these difficulties and looking after their own family. Participants will be asked to take part in a single, one-to-one interview with the researcher. The research is being carried out by Birmingham University. If you would like more details about the purpose of the research and what is involved you can email Dr Hodges directly on RMH033@bham.ac.uk

Appendix 11: Interview Schedule

Interview Schedule
(Adapted from the schedule used in Orford et al..'s 1998 studies)

Section 1 – The Family
Brief outline of who's who in the family

Section 2 – Account of parents drinking/substance use
Brief details of parents past drinking/substance use

Details of current nature of drinking/substance use including how and where alcohol/drugs bought and drunk/taken – recent or significant changes in level or nature of drinking/substance use

Brief outline of participant's drinking/substance use

Section 3 – Effects on the family (including extended/multi-generational family)
Impact/implications of the drinking/substance use on various relationships
 Participant/spouse
 Participant/their children
 Grandparents/grandchildren

Grandparent/grandchildren – (how) is this relationship maintained/encouraged?
 Probe for concerns about the implications of participants' parents behaviour
 for their children (ie, the drinker/substance user's grandchildren)

The role of the sober parent (if there is one) and effects of that person on the participant

The nature of the support/care offered/provided (what is the participant actually doing?)
 How does this compare with how the participant would expect to care for a parent of this age who does not have a drinking/substance use problem?

How does the participant feel about providing the care/support?

Section 4 – Managing/coping
How does the participant balance looking after a parent with looking after their own family?

Have methods of coping changed?

Section 5 - Support
Who else in the family helps/provides support for the drinker/substance user?

From where does the participant receive support?

What else would the participant like in terms of support?
> Family?
> Professional?
> Specific alcohol/drug related or general support wanted?

Section 6 – The future
Participant's fears of the future?

Participant's hopes for the future?
> What would have to happen for the hopes to be realised?

Appendix 12a: Example of line-by-line coding

Participant 1. Andrea
Lines 222-279
I: and what role drink plays in the relationships so like how has your relationship changed with her
R: oh totally totally changed now I mean when I had my son she always looked after him
I: how old is he now
R: he's fourteen now so when he was born she didn't drink for quite a while then quite a long time
I: yeah
R: and errm but that wasn't unusual because that was the pattern at that time that she could go a year or two without drinking
I: what would set it off then if you've gone a year or
R: I have no idea. Anything
I: and she wouldn't know either
R: well she'd say what it is but it would be something stupid like oh your dads gone to golf. Nothing major not a major incident errm and she used to look after Aiden if I did a little bit of work or something so she had a really good relationship then with all of us and she spent a lot of time with him and looking after him and she enjoyed him because he was her first grandson and you know
I: yeah
R: so we probably had a good relationship then errm but there were always times when it was a bit difficult (.) and then now there really isn't a relationship at all now I just have to look at her. I only have contact with her for my dad now
I: yeah
R: I wouldn't have contact with her for any other reason now
I: and what about Aiden and hers relationship
R: well I asked him actually because we try and protect him quite a lot from it. He's never seen her really drunk because I don't see why he should
I: yeah
R: and why put your child through that because there's no reason nothing to gain and I spoke to him about it the other day and I said oh how do you feel about granny and he said well it's an embarrassment and then he said and granddad gets really stressed about it and he has to rush back and so errm I thought oh and it was quite good really that you coming because it actually made us have a little chat about it
I: is he angry or is it sad for him
R: I think a bit of both yes he does get a bit angry about it errm he never says anything when she's there but he doesn't really talk to her anymore and yet he always when he was little obviously he used to say oh shall we go to granny's shall we go to granny's it's sad for him really
I: yeah so he does understand what's happening
R: yeah we spoke to him a couple of we kept it from him for a long time but she kept missing his birthdays and he to start with he got really upset when she missed his birthday and then in the end we just told him because he's very in to sport and there was quite a few

things I can't remember what had happened at the time but there
was a lot about depression in sport
I: right
R: and so I introduced it from that point of view and he so he could
understand it but he knows about the drinking now
I: right
R: so you know were pretty open but I don't let him see it
I: yeah
R: because I think well why worry him

Appendix 12b: Developing initial coding

**Second stage of analysis. Coding initial observations**

Initial observations	Initial codes
Change in relationship over time	Change - difference
Grandmother as carer in parents' absence	'normative' - positive
Positive- related to family	Positive – family
Not special related to baby	Usual for her. Different at different times
What used to be	Change over time
'Normalising' – usual for her	Change over time
Not understand behaviour	Confusion
Frustration	Negative emotion
Looking for explanation	Confusion – looking for explanation
'Normal' family roles	'Normal' family roles
Positive relationships	Positive relationships
Link made – 'normatively' expected	'Normal' family roles
Some positives but not always good	Contrast – change
No relationship with mother	Negative relationships
Role of other (sober) parent	'Normal' family roles - daughter
Reason for contact	Family roles – expectation/duty
Breakdown of relationship	Negative relationships
Reason for contact	Family roles – expectation/duty
Protect son	'Normative' parenting – protect child
Shielded	'Normative' parenting – protect child
No reason	Negative relationships
Protect child	'Normative' parenting – protect child
No gains/no positives	Negative relationships
Embarrassment – negative emotion	Negative emotion
Role of other grandparent – not able to have positive relationship	Disrupted 'normal' family roles.
Change in thoughts/relationships	Change - deterioration
Prompt talk	Not regularly discussed – avoided?
Talk about within family	'Normative' family/parenting – talking
Angry – negative emotion	Negative emotion
Detachment	Negative relationship - detachment
Positive past	'Normative' family – positive – in the past
Sad – negative emotion	Negative emotion
Shielding	'Normative' parenting – protect child
Normative expectation not met	Normative expectation not met
Upset – negative emotion	Negative emotion
Delay – reluctance?	Confusion
Made links to create understanding – reduce confusion/upset	Confusion – looking for explanation
Create understanding	Confusion – looking for explanation
Contrast – open but shielding	'Normative' parenting – protect child
Worry - predicted negative emotion	Negative emotion
Protecting	'Normative' parenting – protect child

Appendix 12c: Developing overall themes

Third stage of analysis. Draw together initial codes across the whole data set

Initial themes	Codes from across data
Roles and relationships	Change over time 'Normative' positive Positive – family 'Normal' family roles Family roles – expectation/duty Disrupted 'normal' family roles Change – deterioration Negative relationships 'Normative' parenting – protect child *(To include codes from other transcripts)*
Emotion	Confusion – looking for explanation Negative relationships – detachment Negative emotion *(To include codes from other transcripts)*
Contact	Family roles – expectation/duty *(To include codes from other transcripts)*

A model depicting the interaction between factors in understanding the relationship.

The themes which appeared to capture the participants experiences were formulated into a model which depicts an interaction between the roles family members play in each other's life, emotions expressed by participants and how these relate to the contact they have with their drinking parent.
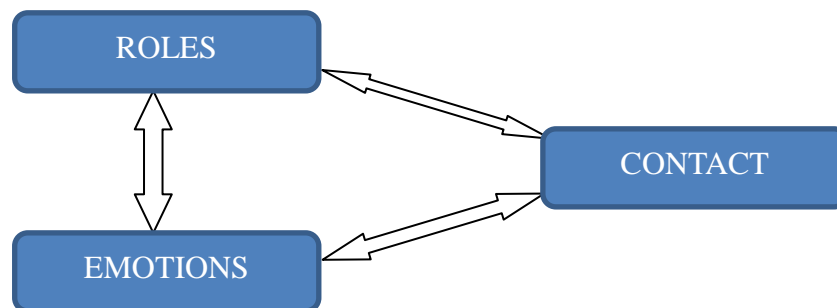
However, the model did not capture the conflict and dilemma expressed in interviews. Dynamic themes created.

Initial themes	Dynamic themes
Roles and relationships	Normative notions of family vs. experience
Emotions	Emotional detachment vs. strong emotion
Contact	Functional/practical contact vs. emotional/relational contact

"How do I tell my children about what my mum's like?": Conflict and dilemma in experiences of adult family members caring for a problem-drinking parent.

Background

Many people find themselves fulfilling the role of carer for their ageing parents. This can often be a difficult situation, especially when the caregiver has other commitments such as a young family of their own.

Research indicates that substance misuse amongst older adults is increasing, however alcohol use disorders in older adults are commonly under-recognised or misdiagnosed by healthcare professionals. Substance misuse in the family affects all of the family members.

As these two factors may indicate, the combined circumstance of caring for an older parent with a substance use problem could be expected to be stressful, but since it is often missed by healthcare or support services this suggests that a significant number of families may be attempting to manage an older adult's alcohol problem without sufficient or appropriate support.

Aim

The study explored the on-going relationship between adults with children and their parents and the ways in which substance misuse problems impact on the intergenerational relationships. The main aim was to understand the experiences of an adult with children who is also providing care or support for their parent who has an alcohol use problem. It was anticipated that this would help to discover what particular stressors may be experienced by this group of people.

Method

Participants were recruited via a number of methods including advertising in alcohol services and carer's groups and through participants introducing their friends or siblings to the study. A one-to-one interview was conducted with six women who had at least one child and cared for their parent who had an alcohol problem. The interviews were audio-recorded and analysed for similarities across the interviews. The analysis concentrated on the women's feelings and experiences rather than generalised statements or facts.

Findings

The findings indicated that the participants appeared to face a number of conflicts or dilemmas in relation to their relationship with their parent. Three themes are described in detail which highlight conflicts related to 'normative notions of family Versus experience', 'emotional detachment Versus strong emotion' and 'functional/practical contact Versus emotional/relational contact'.

Notions of family Versus *experience*

Participants provided images of 'ordinary' family lives and relationships but then indicated that their experience was different from this. For example, participants talked about their parent visiting them in hospital after the birth of their baby which

may be a normal expectation, but many of them then stated that their parent had been "drunk" or "paralytic" at the visit which they experienced as embarrassing or hurtful. The conflict or dilemma participants appeared to find themselves in is feeling trapped in a relationship that has not been nurturing or positive for them and yet feeling the burden of expectation that they should now provide care.

Similarly as parents themselves, participants spoke of wanting their child(ren) to have a relationship with their parent (the child's grandparent), however, the grandparent was described as unpredictable, unpleasant or nasty so the women's over-riding feelings were to protect or shield their child from their parent's behaviour.

Emotional detachment Versus *strong emotion*
Participants talked about how painful it was to maintain an emotional relationship with their parent and had therefore attempted to emotionally detach from their parent. However, this appeared to be very difficult and often produced further feelings of guilt and upset.

It was expressed that for a long time the women held on to a hope that their parent would stop drinking. This hope was particularly strong when they were starting their own family with the anticipation that a new grandchild would prompt their parent to change their drinking behaviour. Each talked about the pain and upset with the realisation that this had not happened.

The dilemma or conflict for participants here appeared to be how to protect themselves and their child(ren) by emotionally detaching themselves from a person or situation that aroused very strong emotions in them.

Functional/practical contact Versus *emotional/relational contact*
The fall-out of the previous two conflicts (described above) appeared to be played out in the contact the participants had with their parent. The conflict faced here was around balancing a relationship that is influenced by the roles, responsibilities and expectations of each of the people in the relationship and the emotions experienced by the women. The women spoke of a move from an emotional relationship with their parent to one which focused on practical activities or fulfilling some obligation. For some, this may be in order to support a sober parent or step-parent who lived with the drinking parent. Participants appeared to be in a state of flux or confusion about aspects of their relationship and contact with their parent. Rather than contact with their parent being through choice or pleasure, participants talked about it being out of duty or through feeling guilty.

Concluding comments
The experiences of adult family members caring for a problem-drinking parent appears to be similar to those of other family members affected by a relative's substance abuse insofar as they experience stress, emotional turmoil and a breakdown in the relationship. However, the participants' particular relationship to the drinker, being the child in need of parental care, an adult daughter faced with an expectation of providing care and a parent providing care to the next generation of family members brought about a number of contrasts. The specific conditions of this situation also

indicated differences between the participants in this study and women providing support to an elderly parent with older-age-related difficulties

The findings reaffirmed the need for support for family members of people with a substance use problem and indicated that the support needed to be timely, as early as possible in the relative's substance abuse career.