

Exploring the impact and harms on families of those experiencing substance misuse: anxiety, depression and mental wellbeing

Executive Summary

November 2015

A report commissioned by Scottish Families Affected by Alcohol & Drugs (SFAD).

This work was carried out by Dr Aisha Holloway (Principal Investigator), Alison Smart (Research Assistant) and Richard Parker (Senior Statistician), The University of Edinburgh.



Introduction

This work was carried out as a direct result of the findings from the Independent Expert Review of Opioid Replacement Therapies (ORT) in Scotland, published in 2013 (1). Scottish Families Affected by Alcohol & Drugs (SFAD) provided the opportunity for the review to engage with families and hear their concerns. The evidence gathered from families was done so via a Conference presentation to SFAD, a Question and Answer session, face-to-face consultation with 20 delegates and also via personal communications. During the process, families were explicit in expressing a need for support and advice that was more easily available. It was evident that families had differing needs at different stages in the recovery process. The following questions were asked by an MSP at the time: Is there research into anxiety and depression in families affected by substance misuse? Is there an increase in psychiatric illness in this group? It was acknowledged that these were thoughtful questions that deserved an answer and that SFAD could be involved in this work.

This report was therefore commissioned by SFAD to explore the impact and harms with regards reported anxiety, depression and mental wellbeing, experienced by families of those experiencing substance misuse. The report provides the results of the scoping research conducted, together with key recommendations to Ministers.

Background

The impact of alcohol and drug misuse in Scotland is significant and growing, not only in relation to individuals themselves, but also to communities across Scotland, including families. The levels of drug misuse in Scotland are double that of England, with alcohol dependency 33% higher than any other part of the United Kingdom (UK) (2). The cost of drug misuse to Scotland's society is assessed at £3.5 billion a year, with the impact of alcohol misuse estimated to cost £3.6 billion (3).

Whilst cost is often considered and calculated at an individual level, there is increasing awareness and cognition of the impact and harm to families as well as society as a whole. A UK wide study focusing on the extent and nature of support provided for adult family members proposed that approximately 134,000 adults had been significantly affected by a relative's drug use. The cost of those harms experienced was reported to be £229 million per year, with the value of support families provide (if it were to be provided by health and social care providers) considered to be £95 million per year (3). Whilst we would acknowledge the important role families play in the life and treatment outcomes of those affected by alcohol and drug misuse, further research is needed to measure the specific impact and harms on families in the first instance.

Policy Context

A range of policy-based publications, acknowledge the contribution of family-based interventions within drug and alcohol treatment settings. These types of interventions benefit not only the individual concerned but also the family and the wider community. However, the involvement of family members in treatment, inclusive of support for family members in their own right, is still only considered as guidance. It has been regarded by some in the drug and alcohol workforce as an aspirational approach as opposed to mandatory, where the primary method of working in this way can move individuals towards treatment and sustained recovery, whilst minimising costs to public services.

(The definition of 'families', refers to 'families and significant concerned others')

Key Policy-based publications
Caring Together. The Carers Strategy for Scotland 2010-2015 (2010)
Changing Scotland's Relationship with Alcohol: An Agenda for Action (2009)
European action plan to reduce the harmful use of alcohol (2012-2020)
Independent Expert Review of Opioid Replacement Therapies in Scotland. Independent Scottish Drugs Strategy Delivery Commission (DSDC, 2013) Scottish Government.
Out of Focus. How families are affected by problem drinking, and how they look for help. Adfam (2013)
Outcomes Framework for Problem Drug Use (2014) NHS Health Scotland
National Drugs Strategy for Scotland (2008) The Road to Recovery – a New Approach to Tackling Scotland's Drug Problem
Quality Principles: Standard Expectations of Care and Support in Drug and Alcohol Services (2014) Scottish Government

Despite a range of policy-based, relevant publications, at grass roots, there remains a disparity in the delivery of family inclusive services across Scotland. This has resulted in some family members receiving excellent interventions in their own right, which has led to positive outcomes for their loved ones in treatment, whilst others have experienced limited or scant access to support services in other parts of Scotland.

The Evidence

The impact that alcohol and drug misuse has on families has long been recognised (4, 5). This has been reported to manifest itself in experiences of stress or trauma-related physical and psychological symptoms (6), resulting in a four fold increase in health-service utilisation in comparison to the average family and more mental health problems when compared to the general population (7). Based on results from the Drug Treatment Outcomes Research Study in England, there are an estimated 1.4 million adult caregivers affected by a significant others drug addiction in the UK (8, 9).

It has been proposed that substance-related problems create chronic 'stresses' for families resulting in 'strain', that in turn creates increased health-care burden. In order to respond to this stress, families adopt methods of 'coping' by reaching out to a variety of available 'social supports' (9). Modes of coping style have been associated with affective well-being e.g. avoidant coping and depressive symptom severity (11). Evidence suggests that family members are willing to engage in formal treatment/counselling in response to their feelings of stress and other co-morbidities suffered as a result of living with someone who has an addiction (12).

However, in a recent qualitative study of carer involvement with drug services in Scotland, the findings identified that carers reported being passed from one service to another, with no-one willing to pick up requests for support or information.

This led a small number to take the initiative of contacting national organisations that offered advice and support to families themselves (13). Support from generic National Health Service (NHS) counselling service, social work or third sector was accessed by very few with some support described as 'sporadic' and with carers divided as to whether this support was in fact helpful. In this study service providers themselves reported providing limited support to carers, with the suggestion that separate services were the best way of ensuring carers received the appropriate support. Despite policymakers emphasising the importance of carer-focused policies, those working locally describe limited and often reactive contacts with carers (13).

What is clear is that there is a greater need for exploration and understanding of the needs of Scottish families of those with substance misuse. With this in mind and following the evidence heard from families as part of the Independent Expert Review of ORT, this work commissioned by SFAD, will provide the first steps in enabling us to build on the evidence base with regards the impact and harms in relation to anxiety, depression and mental wellbeing experienced by families of those with substance misuse in Scotland.

Research Questions

The research reported here aimed to answer two questions:

Alcohol and drug misuse as measured by the:

- i. Hospital Anxiety Depression Scale (HADS) and
- ii. Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Methods and data collection

An interviewer-led survey of 40 individuals' aged 18 years and older living in Scotland, who had responded to an advert for families to participate, was conducted by telephone interview between May 2015 and August 2015. Demographic data was collected alongside information regarding which family member(s) had experienced substance misuse, the nature of their substance misuse and what support families had accessed. The HADS, a 14-item scale which evaluates common dimensions of anxiety and depression and the WEMWBS, a 14-item scale to monitor mental wellbeing, were the data collection instruments used. Each of the 14 item positively worded responses in the WEMWBS are scored from 1 (none of the time) to 5 (all of the time). The total scale score is calculated by summing the 14 individual items scores. The HADS comprises 2 subscales containing 7 questions for anxiety and 7 for depression, with each item scoring 0-3, a total score of 0-21 can be obtained for either anxiety or depression. Neither scales are designed to be a clinically diagnostic tool.

Results

Of the 40 respondents, thirty-eight respondents were female (95%) and two were male (5%), with the majority (40%) coming from Lothian region (n=16) followed by Greater Glasgow & Clyde (n=8) and the remainder spread across regions in Scotland*. Thirty-two respondents were aged 45 or older (86%), with 28 of respondents either married or living with a partner (70%). The vast majority (n=36) of respondents were either employed or retired (90%). Thirty-two respondents identified themselves as White Scottish (80%).

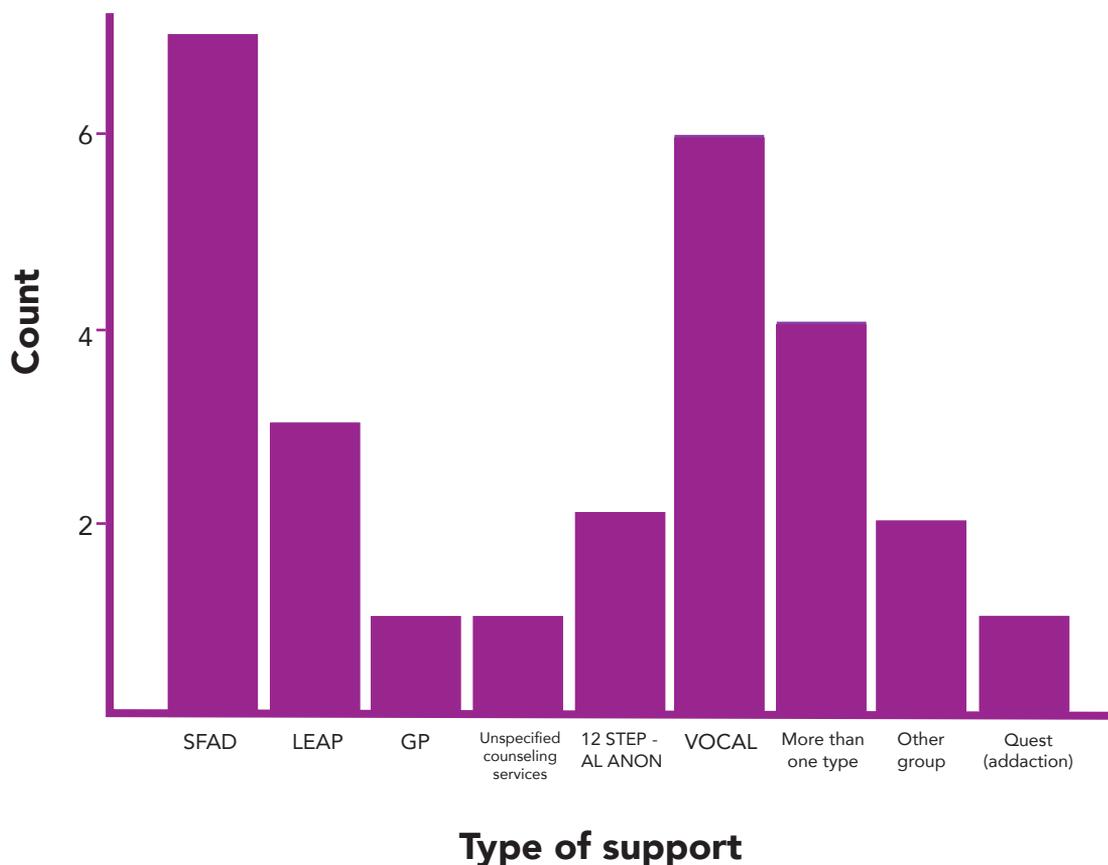
Thirty-six respondents (90%) had one family member with alcohol or drug misuse. Three respondents had two family members with alcohol and/or drug misuse and one respondent reported having three family members affected (daughter, brother and deceased father).

The reported use of drugs only, alcohol only or both drugs and alcohol by a family member were 11 (31%), 14 (39%) and 11 (31%) respectively. The majority of respondents had a son with drug and/or alcohol misuse (36%), others identified were daughter, husband, ex-spouse, mother, partner, wife, grandson, father, brother, deceased father and deceased son. Nineteen respondents (54%) said that their family member had experienced substance misuse for more than 15 years.

Twenty-seven (68%) respondents were currently receiving formal support for themselves, of whom 10 (38%) had been receiving support for over 2 years. The type of support received is shown in Figure 1.

*One participant had recently moved to England but their family remained in Scotland.

Figure 1: Type of formal support accessed



The results of the WEMWBS data are presented in Table 1. Data was available for all 40 respondents.

Table 1

Results: Warwick-Edinburgh Mental Well-being Scale (WEMWBS)
Mean total of WEMWBS was 45.1 (SD 10.4)
Range was 22-70 (Minimum possible score is 14 and maximum is 70)
The mean score for this sample was significantly lower than the general population mean of 50.65†
† General population mean obtained from fourth national Scottish survey of public attitudes to mental wellbeing and mental health problems 2008.

Table 2

Results: Hospital Anxiety and Depression Scale (HADS)
The mean Anxiety and Depression scores were 12.1 (SD 4.8) and 7.7 (SD 4.6) respectively
Twenty six respondents (65%) scored 11+ on the anxiety subscale (categorised as moderate to severe)
Only 8 (20%) respondents scored 0-7 on the anxiety subscale (categorised as normal or no anxiety)
Twenty one respondents (53%) scored 11+ on the depression subscale (categorised as moderate to severe)

Three participants had one missing item each on their HADS scales. For these respondents the missing value was imputed as the mean of the remaining items on the subscale. Total scores were then computed for each subscale: anxiety and depression.

The HADS results are presented in Table 2. The HADS depression subscale scores were significantly lower for those employed compared to all other groups (mean difference 3.14, 95% CI 0.35 to 5.93, p=0.028).

Key Findings

Overall, this was a scoping study with a small sample and therefore the results must be considered within this context. Nevertheless, significant relationships were found with regards some of the data. Overall Key Findings have been drawn from this analysis.

Overall Key Findings

- The average mental wellbeing (WEMWBS) score was significantly lower than the average of the general Scottish population, suggesting lower mental wellbeing on average for respondents
- Sixty-five percent of respondents showed scores of 11+ on the anxiety subscale of HADS, which falls into the moderate to severe category
- Only 8 respondents (20%) reported scores of 0-7 on the anxiety subscale of HADS, which falls into the normal or no anxiety category
- For the depression subscales of HADS, over 50% of respondents had scores of 11+, which falls into the moderate to severe category
- HADS depression subscale scores were significantly lower for those employed, compared to all other groups

The full results of the study will be available in the full report.

Key Recommendations

1. **Assessment and support** - inclusion of families as part of SMART (Specific, Measurable, Achievable, Realistic and Timeous) goals to recognise their specific needs as part of the assessment and support provision in a national approach to drug and alcohol treatment processes.
2. **Monitoring needs and interventions for families** – standardisation and implementation of a national monitoring process of family needs, delivery of interventions inclusive to and for families, with evaluation to measure outcome and impact.
3. **Automatic referrals to family support services** – for families who are present when a significant other is accessing treatment and when it is identified as part of evidence-based recovery approaches, automatic referral to family support services should be offered.
4. **Wider workplace support for families** - better recognition and appropriate support in the workplace for family members affected by problem substance use to help sustain employment.
5. **Map workforce development need** - map workforce development needs in keeping with the Recovery Oriented Systems of Care (ROSC) approach to Family Inclusive Practice (FIP) for those working in the drug & alcohol sector as well as the wider workforce engaging with communities. This will support improved workforce priorities of FIP as part of the ROSC.

References

- 1) Scottish Drugs Strategy Delivery Commission (DSDC, 2013) Independent Expert Review of Opioid Replacement Therapies in Scotland. Scottish Government.
- 2) Taylor, M, Mackay K, Murphy J, McIntosh A, McIntosh C, Anderson Seonaid, Welch K (2012) British Medical Journal Open;2:e000774. Doi:10.1136/bmjopen-2011-000774
- 3) UKDPC (2009) Supporting the Supporters: families of drug misusers. London: UK Drug Policy Commission
- 4) Jackson JK (1954) The adjustment of the family to the crisis of alcoholism. Quarterly Journal of Studies on Alcohol. 15:562-86
- 5) Orford JF (1990) Alcohol and the family: an international review of the literature with implications for research and practice. In: Kozlowski LT, Annis HM, Cappel HD, Glaser FB, eds. Research advances in alcohol and drug problems. New York:Plenum. 10, 81-155
- 6) Lennox RD, Scott-Lennox JA, Holder HD (1992) Substance abuse and family illness: evidence from health care utilisation and cost-offset research. Journal of Behaviour Health Service Research. 19:83-95
- 7) Svenson LW, Forster DI, Woodhead Se, Platt GH (1995) Individuals with a chemical-dependent family member. Does their health care use increase? Canadian Family Physician. 41:1488-93
- 8) Copello AG, Templeton LJ, Powell J (2009) Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses [Online] Available at:<http://www.ukdpc.org.uk/wp-content/uploads/supporting-adult-family-members-of-people-with-drug-problems-in-scotland1.pdf> (accessed November 02 2015)
- 9) Copello A & Templeton L (2012) The Forgotten Carers: Support for adult family members affected by a relative's drug problems. UK Drug Policy Commission (UKDPC)
- 10) Oford JF, Natera G. Davies J et al (1998) Tolerate, engage or withdraw: a study of the structure of families coping with alcohol and drug problems in South West England and Mexico City. Addiction. 93:1799-813
- 11) Finney JW, Moos RH, Cronkite RC, Gamble W (1983) A conceptual model of the functioning of married persons with impaired partners: spouses of alcoholic patients. Journal of Marriage & Families. 45:23-34
- 12) Orr LC, Barbour RS, Elliot L (2012) Carer involvement with drug services. Health Expectations.16, 60-72
- 13) Lee KMTL, Manning V, Teoh HC, et al (2011) Stress-coping morbidity among family members of addiction patients in Singapore. Drug and Alcohol review. 30, 441-447

We would like to thank all those families who took the time to respond and take part in the study.