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Associative Stigma Among Families of Alcohol and Other Drug Users

Olivia Marshall

A Report Submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Arts (Psychology) (Honours), Faculty of Health, Engineering and Science,

Edith Cowan University.

Submitted November, 2013

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Acknowledgements

Table of Contents

ASSOCIATIVE STIGMA FAMILIES AOD USE

Running head: ASSOCIATIVE STIGMA FAMILIES ALCOHOL DRUG USE

Associative Stigma and How it Impacts Families of Alcohol and Other Drug Users: A Literature Review

Olivia Marshall

Edith Cowan University

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Abstract

Stigma is the devaluation of groups and individuals because of traits or behaviours that deviate from social norms. Drug use is a highly stigmatised behaviour, as it is mainly viewed as a controllable behaviour or character weakness. Stigma may occur by association and this is known as courtesy or associative stigma. A comprehensive review investigated associative stigma among families of psychoactive substance users. Searches of psychological databases located articles pertaining to associative stigma among families. Articles located indicated that associative stigma occurs toward families in other populations, such as those living with mental illness and HIV. A lack of research exists with regard to stigma among families of alcohol and other drug (AOD) users. Exploratory studies are needed to ascertain how stigma is experienced by families of AOD users and what impact this has on emotional and psychosocial wellbeing and to inform policy makers regarding service needs.

Associative Stigma and How it Impacts Families of Alcohol and Other Drug Users: A Literature Review

INTRODUCTION

Stigma is a social process where certain groups or individuals are devalued by others because of perceived undesirable attributes (Goffman, 1963). These attributes mark some point of difference or deviation away from the norm (Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984). Commonly this includes perceived dangerousness or weakness of character (Goffman, 1963) as well as non-conforming behaviour (Link and Phelan, 2001; Major & O-Brien, 2005; Room, 2005; Tindal, Cook & Foster, 2010). Stigma leads to social exclusion, which can negatively impact mental and physical health and socio-economic circumstances (Major & O'Brien, 2005; Room, 2005).

Drug use is considered one of the most stigmatised behaviours (Corrigan, Miller & Watson, 2006; Room, 2005). Socially devalued and moralised, alcohol and other drug (AOD) users are perceived as self-indulgent, lacking in self-control and weak-willed (Semple, Grant & Patterson, 2005; Tindal et al., 2010) and hence are viewed as blameworthy and less deserving of treatment (Obot, Poznyak & Monteiro, 2004; Room, 2005). There is also a perception of dangerousness, particularly given media portrayals of drug use being linked with crime (Taylor, 2008) and fear of disease associated with injecting drug use such as HIV and Hepatitis C (Tindal et al., 2010). Although such fears may not be completely unfounded, views such as this overlook the complexities of drug dependence (Obot et al., 2004) and may lead to discrimination (Link & Phelan, 2001).

Some have asserted stigma can befall individuals by virtue of their association with discredited others (Goffman, 1963, Jones et al., 1984). Goffman referred to this as courtesy stigma, whereas others have termed this associative (Mehta & Farina, 1988), or secondary stigma (Ogunmefun, Gilbert & Schatz, 2011). Family members are particularly susceptible given their genetic relationship, as well as their proximity in many cases (Goffman, 1963; Mehta & Farina, 1988). Studies have suggested families may be held to blame by others, or otherwise be seen as contaminated (Corrigan et al., 2006). Moreover, families can be susceptible to self-stigma, where external perspectives of devaluation are internalised and this has been shown to have a deleterious effect on wellbeing (Mak & Cheung, 2008).

Numerous studies have reflected that associative stigma exists among families for other stigmatising conditions such as mental illness (Phelan, Bromet & Link, 1998), HIV (Bogart, Cowgill, Kennedy, Ryan, Murphy, Elijah & Schuster, 2008; Cree, Kay, Tisdall, & Wallace, 2004; Ogunmefun et al., 2011) and other health conditions including intellectual disabilities (Ali, Hassiotis, Strydom & King, 2012) and Alzheimer's disease (Werner, Goldstein, Heinik, 2011). Families of offenders have also been stigmatised by virtue of their association (May, 2000; Farkas & Miller, 2007). Yet, despite drug use being a highly stigmatised condition (Room, 2005) there is a paucity of research relating to stigma experiences within families of AOD users. Consequently, little is known about the impact stigma has among these families or what sort of support is needed for this population.

In order to understand how stigma relates to families of AOD users it is necessary to understand what stigma is; how it occurs; how this relates to AOD users; and how this extends to their families. Therefore, the purpose of this paper is to answer the following four questions: a) what is known about stigma and the theoretical frameworks underpinning this phenomenon? b) what literature exists relating to stigma by association, particularly as this relates to families? c) what does the literature tell us about stigmatisation of AOD users? and d) what research exists pertaining to stigma among families of AOD users?

In answering these questions, I will outline the methods taken for a systematic review of the literature, followed by a discussion of underpinning theories and conceptual frameworks relating to stigma. Due to the paucity of research relating to families in the AOD area, I will canvass a broader consideration of research relating to family stigma, followed by a discussion regarding the stigmatisation of AOD users. Finally, I will examine existing studies pertaining to stigma by association among families of AOD users. Findings will show that research in this area is lacking, indicating a need for exploratory studies.

METHOD

SEARCH STRATEGY

I searched electronic databases PsycInfo, PsycArticles, ProQuest, Pubmed, Medline and DrugDatabase for peer reviewed articles. Keywords used to search for information relating to stigma

theory were "stigma", "stigmatisation" and "stigma theory". I broadened this search to locate articles relating to family stigma and keywords used were "family stigma", "courtesy stigma", "associative stigma", "affiliate stigma", "secondary stigma" and "stigma by association". I then paired these terms using Boolean operators of "AND" and "OR" with "substance use", "drug use", "alcohol use", "drug dependence/y", "alcohol dependence/y", "drug addiction", "alcoholism" and "substance abuse", as well as simply "drug" and "alcohol". Titles and abstracts were reviewed and articles selected based on relevance to family stigma. Articles located that related to family stigma were also manually searched for references. Studies found were analysed in terms of methods used and outcomes obtained.

RESULTS OF SEARCH STRATEGY

The search for articles pertaining to stigma by association yielded a total of 635 articles. Of these, 170 were selected for further review by title and/or abstract. A cross-reference was made and 90 articles were duplicates, leaving a total of 80 articles. A further 15 were included after hand-searching. One article was excluded because it was written in German. Other articles were removed because they did not meet criteria in other ways, specifically that 'family stigma' pertained to family as the stigmatisers ($N = 3$), or were examined from the perspective of the primarily stigmatised ($N = 2$). Discussion papers were also removed ($N = 4$). The remaining articles pertained to family stigma in various domains, predominantly mental health (16) and HIV ($N = 17$). Mental health studies specified related to schizophrenia ($N = 6$), bipolar disorder ($N = 2$), depression ($N = 2$) and psychosis ($N = 4$). Three studies related to both mental illness and intellectual disability.

Other studies reported on stigma for families living with illnesses such as Alzheimer's disease ($N = 5$), intellectual disability ($N = 5$), congenital physical handicap ($N = 2$), ADHD ($N = 3$), anorexia nervosa ($N = 2$), autism spectrum disorder ($N = 3$), dementia ($N = 1$), suicide ($N = 1$), death ($N = 1$), disability ($N = 1$), developmental disorders ($N = 1$), Sickle Cell Disease ($N = 1$), physical deformity ($N = 2$), obsessive compulsive disorder ($N = 1$) and Proteus syndrome ($N = 1$). Two studies related to stigma toward family members of offenders. Five studies were also found relating to family stigma and substance use. However, two of these were comorbid studies (mental illness and substance use), and one classified substance use among other mental health issues, therefore results were not specific to AOD use.

Two studies were non-specific. One measured public perspectives toward alcoholism among various other stigmas. The other examined the psychological impact of 13 different concealable stigmatised identities, with one of these being the substance misuse of a family member. The remaining study pertained to parents of adolescent problem drug users.

THEORETICAL UNDERPINNINGS OF STIGMA

Numerous social psychological theories help to explain the process of social stigma. Most prior research has taken a social cognitive approach, examining the thought processes involved between individuals for stigma to occur (Yang, Kleinman, Link, Phelan, Lee & Good, 2007) and in particular the processes of stereotyping, prejudice and conformity (Tajfel, 1974). Social cognition theory is based on how individuals store and process information about others and in turn how this influences their perceptions and interactions (Tajfel, 1974). This approach considers the cognitions of both the stigmatised and the stigmatiser, with view to understanding the overlap between the two for stigma to occur. For instance, Jones and colleagues (1984) discussed the emphasis placed on the stigma as well as congruence between parties as being important factors for stigma to become part of the self-concept.

However, some have argued the social cognitive approach in isolation provides an incomplete analysis of stigma by failing to consider the significance of intergroup behaviour and social structure in relationships (Campbell & Deacon, 2006; Yang et al., 2007). Social identity theory on the other hand acknowledges the social structure within which phenomena such as stereotyping and prejudice arise (Tajfel, 1974). Although social cognition and social identity have often been described as opposing theories, when combined they provide a more comprehensive understanding of the processes involved in social stigma, by bridging the individualistic processes of cognitive thought and the social phenomenon of group behaviour (Abrams & Hogg, 1999). This explains why stigma processes are commonly explicated using two prominent models, one of which has a social cognition focus (Corrigan &Watson, 2002), whereas the other has a sociological basis (Link & Phelan, 2001).

Extending from social cognition theory, attribution theory provides a key aspect in explaining the stigma process. Attribution theory as applied to motivation and emotion is based on "the concept of causal ascriptions" (Weiner, 1986, p.3). According to Weiner, Perry and Magnusson (1988), attributional

analysis involves an assessment about outcome, such as social rejection or acceptance, followed by inquiry as to the causality of this outcome. If the cause is perceived as being beyond the individual's control a positive response may be elicited, such as sympathy or pity. However, if the individual is believed to have caused a negative outcome, such as with drug use, negative affect may be elicited and manifest in anger, avoidance or the withholding of assistance (Weiner et al., 1988).

DEFINITIONS AND CONCEPTUAL MODELS OF STIGMA

Stemming from Greek origins, the term stigma was originally used to describe a physical mark denoting negative moral status (Goffman, 1963). However, according to Goffman there had been no real scholarly pursuit to define and conceptualise stigma in contemporary terms, prior to his seminal writings on the 'spoiled identity'. Heralding from a sociological background, Goffman defined stigma as "an attribute that is deeply discrediting" (p.3), or something which makes a person seem undesirable, tainted or less of a whole person. The social context of stigma was emphasised by Goffman, highlighting that it is not a language of attributes, but rather one of relationships which underpins this process.

The three main types of stigma according to Goffman (1963) are abominations of the body or any sort of physical abnormality; blemishes of individual character such as dishonesty or weak will; and tribal stigma which refers to race, nation and religion. These attributes may lead to a sense of justification for less humane treatment of such individuals, resulting in discrimination and other forms of social disadvantage (Goffman, 1963). In the case of AOD users the classification of blemished character is deemed most relevant. For families of substance users, tribal stigma is most relevant, suggesting that stigma "can be transmitted through lineages and equally contaminate all members of a family" (Goffman, 1963, p.4).

A subsequent conceptualisation of stigma formulated by Jones and colleagues (1984) is also commonly cited in the stigma literature. This model is informed by a social cognitive perspective, with a focus on the cognitive and affective underpinnings of social relationships and how these shape behaviours. It was suggested that "impression engulfment" (p. 9) is the essence of stigma, a process occurring when the deviant condition is considered integral to the marked person's identity. Whilst Jones and colleagues recognised the importance of social consensus in these views being sustained, the main focus remained on

the cognitive categorisations of the players, the "marked" and the "markable", (p. 8) in terms of how stigma takes place.

The model postulated by Jones et al. (1984) incorporates six dimensions of stigma; concealability, course, disruptiveness, aesthetic qualities, origin and peril. These dimensions identify the variations among stigmatising conditions, as well as how they influence social interactions where a stigmatising condition is involved. The first dimension refers to the ability to conceal the condition, highlighting that the easier this is, the more likely this approach will be taken. The course of the mark determines the likelihood of the condition changing over time and how this affects the outcome. For example, if an illness or condition is thought to be incurable, the stigma is unlikely to decrease, and vice versa. The origin dimension has a causality aspect and a focus on responsibility, whereas peril designates a sense of danger, threat or unpredictability (Jones et al., 1984). Notably, in a review of studies of public perspectives on the mentally ill, Angermeyer and Dietrich (2005) found that dangerousness and peril are two aspects of stigma that evoke a greater desire for social distance. This is particularly so for a mental illness such as schizophrenia where such labels are readily applied, but also for individuals with alcoholism or a drug addiction.

The dimensions of course, origin and peril are perhaps the most relevant in terms of stigma toward drug users and their families, as numerous studies have suggested that drug users are viewed as being dangerous and unpredictable (Angermeyer & Dietrich, 2005) as well as being responsible for causing their illness (Corrigan, Kuwabara & O'Shaughnessy, 2009). Weiner and colleagues (1988) found empirical evidence for the dimensions of course and origin in their study on attributions toward those with a stigmatised condition. Their study involved two experiments. The first included 59 male and female university students who completed questionnaires relating to stigma. Stigmatised conditions included AIDS, Alzheimer's disease, blindness, cancer, child abuse, drug addiction, heart disease, obesity, paraplegia and Vietnam War syndrome and were classified as being physical or mental-behavioural. The questionnaire had three indices, based on constructs of causal properties and controllability of stigma; affective responses relating to perceived controllability and stability of the stigma (including pity, anger, liking, charitable donations and personal assistance); and interventions presumably linked with causal stability (such as job training, professional training and education, welfare, medical treatment and

psychotherapy). Ratings were made for all variables using 9-point scales, although rigour was lacking as there was no comment made regarding the reliability and validity of the instrument used. A pattern of associations was found between the source of the stigmas, perceived controllability, affective reactions and judgements about provision of help (Weiner et al., 1998). Stigmas such as blindness, which were perceived to be uncontrollable, evoked pity and were deemed as worthy of charitable donations. On the other hand, stigmas perceived as controllable, such as drug addiction evoked high anger and little pity, with low judgement regarding provision of assistance and charity (Weiner et al., 1998).

A second study was conducted as the first experiment was correlational and did not allow for causal inferences to be drawn. Participants were obtained from an American university (*N* = 149*)* and a Canadian university (*N* = 171). Directional relationships were tested by manipulating information about the responsibility for the onset of the stigmatised condition. For example, AIDS was either the result of a blood transfusion or promiscuous sex life. Overall, it was found that perceived attributional characteristics influenced the way individuals respond to a stigma. This related specifically to controllability and stability, or as termed by Jones and colleagues (1984), the course and the origin of the mark. This study demonstrated that greater pity, help giving and liking is elicited if the stigma is deemed onset-uncontrollable and it was concluded this was because participants believed onset-controllable or mental-behavioural stigmas were indicative of weak will and character (Weiner et al., 1998).

Two theoretical frameworks of stigma have been empirically tested using large population samples. These models are the most commonly drawn upon to explain the stigma process (Angermeyer & Dietrich, 2005; Corrigan, Kuwabara & O'Shaugnessy, 2009). The first is Corrigan and Watson's (2002) social psychological (cognitive) model which posits that stigma arises from a process of stereotyping, prejudice and discrimination. This has also been described as a cognitive, affective and behavioural process (Corrigan & Watson, 2002; Mak & Cheung, 2008). First, the individual becomes aware of certain stereotypes about groups or individuals, (drug addiction is the result of bad parenting), which may or may not be endorsed. Prejudice is the evaluative component, as it involves an endorsement of negative stereotypes (I agree drug use stems from bad parenting). Discrimination is the behaviour by which this prejudice is enacted (I'm going to avoid that family because their son is a drug user) (Corrigan & Watson, 2002).

This model was initially formulated to explain the phenomenon of public stigma, defined by Corrigan (2004) as "ways in which the public reacts to a group based on based on stigma about that group" (p.114). It has been applied and empirically tested mainly using vignette research designs (Corrigan, Watson & Barr, 2006; Corrigan et al., 2009). Corrigan and Watson (2002) suggested the model also explains the process of self-stigma, an internalisation of stigmatising public beliefs and attitudes. Self-stigma has been described as a three-level process of stereotype agreement, self-concurrence and self-esteem decrement (Corrigan et al., 2006). The model was tested by Corrigan et al. (2006) on two samples with psychiatric disabilities ($N = 54$ and $N = 60$ respectively). The scale used (Self-Stigma of Mental Illness Scale) was found to be reliable and valid for this population (Cronbach's α between 0.72 and 0.89). In a subsequent study the instrument was adapted for use among a sample of alcohol dependent individuals. The authors claimed the tool showed good reliability and validity, however, did not provide any values to support this (Schomerus, Corrigan, Klauer, Kuwert, Freyberger & Lucht, 2011).

The second model has a sociological influence. Link and Phelan's (2001) conceptualisation posits that stigma occurs through individual mechanisms, structural discrimination and internalisation. There are five components integrating both individualistic and social processes. The first component suggests human differences (social, economic & cultural factors) are identified and labelled. The second component involves a process of stereotyping, where the label links the person or group to undesirable characteristics which form particular stereotypes. The third component involves the labelling group distinguishing themselves from the labelled or stigmatised group, forming 'us' and 'them' beliefs. Underlying this is the belief that the 'out' group are inherently different from the 'in' group and there can be a dehumanising aspect to this in extreme cases (Link & Phelan, 2001).

The fourth component involves discrimination and status loss. It is proposed by Link and Phelan (2001) that the application of negative labels and stereotyping allows justification for individuals or groups to be devalued and socially excluded. Beliefs and attitudes underpinning negative labelling can become overt, leading to discrimination, disadvantage and reduction in life chances. This can affect income, education, psychological wellbeing, medical treatment and health in general. The stereotype may also be believed by the stigmatised individual, possibly leading to low self-esteem, fear of rejection, depression and anxiety, and a generally compromised quality of life. Furthermore, the stigmatised person

may begin to behave in a manner akin to the stereotype and become less likely to challenge discriminators (Link & Phelan, 2001).

The fifth component of power is a key aspect of the model and perhaps what differentiates this from social cognitive models. There is emphasis that the stigmatising group always has greater social, political or economic power, given that stigmatised populations are generally represented by minority groups (Link & Phelan, 2001). Link, Yang, Phelan and Collins (2004) conducted a large review of empirical studies (*N*= 109) measuring mental illness stigma by applying Link and Phelan's (2001) model. They found that most studies measured stigma using at least one of the components in the model. However, it was highlighted that the model is missing a component to reflect the emotional impact of stigma, which was suggested as being critical in understanding the behaviour of stigmatisers and recipients (Link et al., 2004).

STIGMA BY ASSOCIATION

In his classic formulation, Goffman (1963) referred to stigma by association as courtesy stigma, suggesting any form of connectedness may invite the same prejudice and discrimination as the marked individual. As Goffman illustrated, "the loyal spouse of the mental patient, the daughter of the ex-con, the parent of the cripple, the friend of the blind, the family of the hangman.. are all obliged to share some of the discredit.." (p.30). Connectedness is therefore defined in various ways, but by this definition, mainly relates to family members. To better understand such experiences of associative stigma, particularly as it relates to families, studies in various areas have been examined.

In examining the literature, it became apparent that certain terms have become common nomenclature to discern the experiences of associative stigma by family members, as opposed to individuals experiencing a primary stigma. Specifically, the phenomenon of public stigma, or the negative views of the general public experienced by families, has generally come to be termed 'family stigma' (Corrigan & Miller, 2004), therefore this term will be applied here. Also, it is noted the term 'affiliate stigma' has been applied to the internalisation of stigma by family members, to differentiate from the concept of self-stigma (Mak & Cheung, 2008). Therefore, this term will be used to discuss the internalisation of stigma for family members.

AFFILIATE STIGMA

Just as individuals subject to a primary stigma may self-stigmatise, awareness of the negative societal attitudes inherent in public stigma toward family members, such as blame, shame and contamination (Corrigan & Miller, 2004; Corrigan et al., 2006) may have the same impact on family members. Qualitative research on families with mental illness has suggested that stigma toward family members may lower self-esteem (Wahl & Harman, 1989), fuelling feelings of shame, guilt and helplessness (Angermeyer, Schulze & Dietrich, 2003). The term 'affiliate stigma' was coined by Mak & Cheung (2008) to refer to the internalisation of associative stigma by family members. This is opposed to self-stigma which applies to individuals internalising a primary stigma (Corrigan & Watson, 2002), or the public stigma felt by families (Corrigan & Miller, 2004; Werner & Shulman, 2013).

Noting that most research in this area had been qualitative, Mak & Cheung (2008) designed an instrument to measure affiliate stigma. In accordance with other stigma conceptualisations (Corrigan & Watson, 2002), the instrument is based on cognition, affect and behavioural psychological responses. Cognition depicts perceptions of lowered worth; affect as feelings of shame and despair; and behaviour as actions in response to stigma such as withdrawal (Mak & Cheung, 2008). Their study involved two samples of caregivers (mainly mothers), the first caring for family members with an intellectual disability and the other for mental illness. The instrument was found to be reliable for both populations (Cronbach's α .095 and 0.94 respectively) and able to measure cognitive, affective and behavioural aspects of affiliate stigma. High levels of affiliate stigma were found to manifest as a sense of shame, inferiority and lack of self-worth resulting from association with a stigmatised person.

Although research in this area is scarce, more recent studies have applied this measure to investigate affiliate stigma in similar populations, such as families of intellectually disabled persons (Chiu, Yang, Wong, Li & Li, 2013), intellectually disabled and mentally ill (Chou, Pu, Lee, Lin & Kröger, 2009; Mak & Cheung, 2012) and among caregivers of individuals with developmental disabilities (Dehnavi, Malekpour, Faramarzi & Talebi, 2011; Mak & Kwok, 2010; Werner & Shulman, 2013). An extensive review on measures of stigma and intellectual disability reported that the Affiliate Stigma Scale (ASS) was found to have good construct validity (Werner, Corrigan, Ditchman & Sokol, 2012). Chou et al.

reported excellent internal consistencies for caregivers in their study (Cronbach's α = 0.94) and Werner & Shulman also reported high internal consistency (Cronbach's α = 0.93). These studies revealed that perceived controllability, responsibility and self-blame were pathways through which family stigma was internalised to become affiliate stigma (Mak & Kwok, 2010). It was also noted that older caregivers reported higher levels of affiliate stigma, most likely due to lengthier periods of care and therefore a greater time to be impacted by family stigma (Chiu et al., 2013). These studies concluded that affiliate stigma contributed to psychological distress (Mak & Cheung, 2012) and diminished quality of life (Chou et al., 2009).

Mainly using surveys, several large quantitative studies have suggested psychological distress results from both perceived and enacted stigma (Meiser, Mitchell, Kasparian, Strong, Simpson, Mireskandar, Tabassum & Schofield, 2007) and also that concealing and social withdrawal are a common means of avoiding negative judgements (Shibre, Negash, Kullgren, Kebede, Alem, Fekadu, Medhin & Jacobsson, 2001; Van der Sanden, Bos, Stutterheim, Pryor & Kok, 2013). Other studies have revealed an awareness of others distancing themselves due to family stigma (Quinn & Chaudoir, 2009; Angermeyer et al., 2003). Whilst concealing has been reported by some as a functional means of avoiding stigma (Phelan et al., 1998) other studies have shown that concealing may in fact create considerable added stress for families, given the difficulties inherent in maintaining a secret and suppressing information (Pachankis, 2007; Quinn & Chaudoir, 2009). Moreover, concealing created a sense of isolation as well as inhibiting access to social support networks, often crucial in assisting families to cope (Bogart et al.,2008; Ogunmefun et al., 2011).

While individuals may be aware of stereotypes and also of prejudiced views, research has suggested they may not necessarily endorse these views (Corrigan & Watson, 2002; Corrigan et al., 2006). Without this subjective internalisation of such views, self-stigma may be avoided (Corrigan & Watson, 2002). Some individuals may remain indifferent or otherwise actively retaliate with "righteous anger" (Corrigan & Watson, 2002, p.38). This alternative response to stigma may motivate individuals to advocate against prejudice and discrimination, as has been demonstrated in civil rights and gender equality movements (Corrigan & Watson, 2002). However, this construct has not been empirically tested. Notwithstanding, some research has suggested family members have adopted this approach, by actively

resisting associative stigma (Poindexter, 2005) or otherwise simply not experiencing stigma due to non-endorsement of stigmatised views (MacRae, 2008; Wong, Davidson, Angling, Link, Gerson, Malaspina, McGlashan & Corcoran, 2009).

FAMILY STIGMA

Numerous studies, both qualitative and quantitative examined the experiences of stigma by association among family members. The four types of stigma experiences revealed in a large qualitative study of relatives of schizophrenia patients were interpersonal interaction, structural discrimination, the public image of mental illness and access to social roles (Angermeyer et al., 2003). Stigma was experienced through interaction with mental health professionals and social exclusion from neighbours, friends and extended family. Structural discrimination was highlighted through the provision of poor care facilities, discriminatory legislation and lack of crisis support facilities. The media was also flagged as propagating negative representations and feeding public ignorance (Angermeyer et al., 2003). Similar findings were made in a large qualitative study of family members of mentally ill relatives, where avoidance by others was experienced, as well as poor treatment by mental health professionals and again the media was emphasised as playing a part in promoting negative images about mentally ill people (Wahl & Harman, 1989).

Studies based on families living with HIV/AIDS also reported interpersonal discrimination such as verbal insults and violence (Bogart et al., 2008), as well as finger pointing and jeering, and being targeted for gossip (Ogunmefun et al., 2011). A qualitative study conducted interviews to investigate the experiences of children with HIV parents (Cree et al., 2004). The study revealed that the children formed different coping strategies with regard to concealing and whether or not to disclose. Openness fostered peer support in some cases as well as an ability to challenge discriminatory social attitudes, whilst on the other hand it left children vulnerable to abuse or rejection (Cree et al., 2004). A further qualitative study revealed that parents living with HIV also had to balance the decision whether to disclose to their children, in order to protect them from discrimination and this caused considerable psychological distress and strained relationships (Madiba, 2013).

Social distancing is a common reaction to stigmatised conditions. Avoidance by others is a measure often employed to determine family members' perceptions of how others relate to them when a stigma becomes known (Angermeyer & Dietrich, 2005; Green, 2003; Werner, Mittelman, Goldstein & Heinik, 2011). For example, in a study on adult children of Alzheimer's outpatients, adult children noted others avoiding them after learning of their parent's diagnosis (Werner et al., 2011). An additional study on families of mentally ill people reported that avoidance was experienced mostly by spouses, but some other family members reported no avoidance at all, showing reactions may differ according to relationship (Phelan et al., 1998).

Families of offenders have also reported experiencing associative stigma. A qualitative study conducted in-depth interviews with eight family members of convicted murderers, revealing that families used three strategies to manage their interactions with the community to avoid stigma (May, 2000). This involved managing space, information and self-presentation. It was found these strategies would often be interwoven and employed in different ways based on context and assessment of risk and reward. For example, managing space involved avoiding places where abuse may occur, which often led to social withdrawal. Managing information, on the other hand, involved strategies such as selective or therapeutic disclosure (May, 2000).

CAREGIVER BURDEN AND STIGMA

Many studies examined stigma in relation to caregiver burden, although this was approached in various different ways. For example, some studies examined stigma among families caring for a significant other with mental illness (Ohaeri, 2001; Goncalves-Pereira, Xavier, Wijngaarden, Paoila, Schene & Caldas-de-Almeida, 2013; Chang & Horrocks, 2006), HIV/AIDS (Hejoaka, 2009) or disability (Green, 2003), by measuring stigma as a contributing factor to subjective caregiver burden. Other studies measured stigma as a separate construct, rather than contributing to burden (Aga, Fekadu, Kylmae, Jari, Nikkonen, Merja, 2009; Mak & Cheung, 2008; Mwinituo, Stevens, Demi & Ayres, 2006). Another study considered stigma and burden of mental illness upon family members, without differentiating between the two constructs (Ostman & Kjellin, 2002).

It was suggested by Corrigan and Miller (2004) that the impact of stigma and burden on the family should be differentiated. First, they suggested the term burden itself may purvey prejudice, in that it denotes some onus of responsibility on families for their loved one's illness. Impact is proffered as a more appropriate and less value-laden term. It was also suggested differences need to be discerned between objective and subjective impact, noting that objective impact characterises the hardships and demands faced by families living or interacting with persons with a stigmatised condition, such as mental illness or disability, whereas subjective impact relates to the family member's own assessment of the circumstances, aside from these other issues. The difficulties in isolating the harm caused by stigma among these other variables were highlighted. For example, family members may distance themselves because of stigma, or otherwise due to support fatigue (Corrigan & Miller, 2004), or possibly a combination of these factors. Although some studies, albeit in different domains, have conducted discrete analyses of these constructs, (Mak & Cheung, 2008; Werner et al., 2012), others have not (Ostman & Kjellin, 2002). Therefore future research may provide some clarity in this area.

STIGMATISATION OF ALCOHOL AND OTHER DRUG USERS

The prevailing view that drug addiction stems from bad choices or a lack of will is widely acknowledged (Room, 2005). A 2001 WHO study illuminated global perceptions of drug use, where a series of 18 topics were ranked according to social disapproval among 14 different countries (Room, Rehm, Trotter, Paglia and Ustun, 2001). Drug addiction was ranked the highest in most countries, noting that it received greater disapproval than having a criminal record for burglary in 11 of the 14 countries. Alcoholism ranked closely behind for most countries (Room et al., 2001). It was concluded a theme of personal responsibility is attached to drug addiction, which underpins a general belief that drug users are less deserving of health treatment and this has been described as a mechanism of stigma where social exclusion has a direct effect on health status (Room, 2005).

In a systematic review of public attitudes towards mental illness, Angermeyer and Dietrich (2005) found that social rejection was higher toward individuals with drug abuse or alcoholism compared than those with depression or anxiety disorders. People with alcoholism and schizophrenia were also

considered to be more dangerous and unpredictable, evoking fear and social distance desirability (Angermeyer & Dietrich, 2005). Moreover, when compared with other perceived controllable stigmatised conditions, such as smoking and obesity, substance use elicited a greater desire for social distance (Phillips & Shaw, 2013).

The stigma attached to substance use is significantly underpinned by ideas of onset and offset controllability and causality (Weiner et al., 1989). Corrigan and colleagues (2009) conducted a study using a large population sample and found people addicted to drugs were viewed as more responsible for the onset of their disorder than those with a mental illness or with a physical disability (in a wheelchair). People with drug addictions were perceived as more dangerous and frightening, were less likely to be offered any assistance and were more likely to be avoided by others (Corrigan et al., 2009).

FAMILY STIGMA – DRUG AND ALCOHOL USE

Despite the stigma associated with AOD use, an extensive search of the literature yielded little information regarding stigma among families of AOD users. In total, six articles were located. Five studies were quantitative and one was qualitative. Four studies were conducted from the perspective of the family member, whereas two investigated public views toward families with an AOD dependent relative. These studies will be discussed in further detail.

A global study used the World Mental Health Survey [WMHS] Consortium Multi-Site to measure stigma via feelings of family embarrassment relating to a family member's illness (Ahmedani, Kubiak, Kessler, de Graaf, Alonso, Buraffaerts, Zarkov, Viana, Huang, Hu, Posada-Villa, Lepine, Angermeyer, de Girolamo, Karam, Medina-Mora, Gureje, Ferry, Sagar & Anthony, 2013) . Illness was categorised as a general medical condition [GMC] (cancer, heart problems, permanent disabilities and other chronic illnesses), or an alcohol, drug or mental health condition [ADMC] (serious memory problems, mental retardation, alcohol or drug problems, depression, anxiety, schizophrenia or psychosis, manic depression, and other serious mental health problems). Although the WMHS was administered to 120 000 people across 23 global sites, a sample of 81 144 people across 16 sites provided data in relation to a specific family burden module of the survey. They were directed to this module after indicating they had a family

member with a medical condition. If affected by the condition they were directed to a series of other questions which included an item about family embarrassment.

It was found that 49.5% of the family members with the ADMC condition felt embarrassed and 36.6% of the GMC and ADMC combined were embarrassed by their family member's illness. This result does not provide any great insight with regard to stigma among family members. A significant flaw in ascertaining the relationship of stigma pertaining to alcohol or other drug use is the lack of discrete analysis between the different types of mental disorders. This type of generalised assessment of mental illness has been criticised by others as holding little value, given the marked differences between disorders (Angermeyer & Dietrich, 2005), coupled with the greater devaluation of alcohol and other drug use as demonstrated in other studies (Room et al., 2001).

One study examined the burden among family caregivers of women with substance use disorders, as well as co-occurring substance and mental disorders (Biegel, Ishler, Katz & Johnson, 2013). This survey study purposively sampled 82 women participating in an outpatient or residential substance use treatment program and they were asked to nominate the family member who provided the most social support to participate in the study. Treatment time was a minimum of three weeks. Stigma was examined as a contributing stressor to subjective caregiver burden, along with worry and displeasure. Objective burden was measured as impact. A stigma scale measured perceptions or worries about how caregivers would be treated by others if they knew about the substance use issue in their family.

The study found that receiving less interpersonal help predicted higher levels of stigma. However, caregivers in this sample experienced greater worry and displeasure than stigma and impact. There was no relationship between caregiver burden and duality of disorder or whether it was a substance use disorder alone, which suggests burden for caregivers may be comparable across domains. A study limitation included time of treatment, given that family members may have only been in treatment for a short time. There was also no indication of whether patients were first time admissions and how this may have contributed to stigma experiences of caregivers (Biegel et al., 2013).

The stigma experiences of families living with mental illness or drug dependence was approached by Corrigan et al. (2006), by measuring the perspectives of the community toward these conditions from a

public stigma perspective. The study was designed to examine the type and extent of stigma experienced and whether this altered according to family role. A survey was provided to 1307 individuals in a population-based sample, but only 74% were completed. Respondents were randomly provided with a vignette which varied across four conditions; the disease of the person with the disorder - mental illness (schizophrenia), drug dependence, or emphysema; the family member (spouse, parent, children, sibling); gender of the person with the disorder; and gender of the family member. Based on previous studies (Corrigan & Miller, 2004), the stigma experienced by families was measured via concepts of blame, shame and contamination. Corrigan and colleagues (2006) found that families of drug dependent individuals were the most stigmatised and harshly judged, particularly as they are seen as blameworthy for the onset of the disorder. Parents and spouses were seen as being more responsible, not only for onset but also for relapse into drug use. Family, particularly children, were seen as likely to be contaminated by their family member's drug use (Corrigan et al., 2006).

The only qualitative study located examined the experiences of a convenience sample of parents of drug using adolescents, based on ethnographic techniques such as observation, personal journal keeping by participants and semi-structured interviews (Barton, 1991). The study applied a sociological theoretical framework, examining the nature of parents' role reformation after becoming aware of their child's substance abuse issues. Adolescent children had entered treatment programs for their drug use and the parents had joined a parent support group. Approximately 20 to 30 parents were observed during weekly meetings over a six-month period and the attendees varied week to week. Of these groups, 10 parents agreed to keep a personal journal reflecting on the experience of becoming aware of their adolescent's drug problem; the initial experience of entering the group; experiences which had differed since others had become aware of the drug problem in their family; and a self-appraisal of the alteration of their parenting since becoming aware of the drug issue. Three couples agreed to subsequent semi-structured interviews to clarify meanings of the journal entries (Barton, 1991).

Results were broken into three sections, discussing role discrepancy, role typification and role validation. It was found parents had difficulty adjusting to their new role as this required them to recognise a discrepancy between their child's prior repute as a 'normal' middle-upper class adolescent, to a drug abusing adolescent, which in turn impacted on the parents' sense of identity. Peer groups were

important for parents to share their experiences, build new parenting skills and develop new attitudes to deal with their situation. Findings demonstrated that parents were less discredited by friends and social supports than by formal community services, such as courts, police and schools (Barton, 1991).

Using vignettes, Mehta and Farina (1988) assessed whether stigma relating to parents would carry over to their college student children. The study examined responses to a hypothetical scenario of a same gender roommate from 120 male and female subjects. The roommate's father was described as having one of six problems – depression; alcoholism; currently in prison for tax fraud; old; has only one leg; and father working away. Participants were asked to comment on how these problems may impact on school, friends, career and family. Support was found for the associative stigma construct, as it was perceived that fathers with depression, alcoholism or who were in prison were likely to create more difficulties for their children than those with other stigmas.

Finally, Quinn and Chaudoir (2009) conducted two studies to examine psychological distress arising from four different stigma-identity related factors - anticipated stigma; centrality of the stigmatised identity to the self; increased salience of the stigmatised identity; and stigma identities with greater cultural devaluation. The first study included 300 participants with 13 different concealable identities and sought to identify how these stigma-identity factors contributed to psychological distress. The second study aimed to replicate findings and to investigate possible physical health outcomes. It involved 235 participants. In both studies combined, 32 participants' concealed stigmatised identity was a family member with AOD addictions.

It was found anticipated stigma and centrality had the strongest effect on psychological distress and furthermore that anticipated stigma had a direct and negative effect on both physical health and psychological wellbeing (Quinn & Chaurdoir, 2005). With regard to centrality, it was found distress occurred as the act of concealing did not allow the individual to access group support, which often is available if the identity is not hidden. Also, in terms of salience and anticipated stigma, it is noted that distress may increase due to increased cognitive action required to hide what may be deemed an important part of the self. Although cultural stigma did not predict distress, it was related to physical health issues.

Overall, psychological distress increased according to the level of the stigmatised identity (Quinn & Chaudoir, 2005).

Although the final two studies contribute some information to understanding how stigma impacts on families living with addiction, the information is not specific because other stigmatised conditions were included. Moreover, the quantitative nature of most studies located has failed to capture specific details of stigma experiences from family members' perspectives. The only qualitative study yielded for this review was limited to the experiences of parents of adolescent children. Therefore, nothing is known about the experiences of other family members living with a relative with an AOD problem and exploratory studies in this area are needed.

SUGGESTIONS FOR FURTHER RESEARCH AND CONCLUSION

In this paper I investigated the concept of stigma, specifically how the phenomenon has been approached in research from a theoretical perspective. I found that stigma research has been largely informed by social cognitive and social identity theories. I examined the construct of stigma by association, with particular focus on family stigma. Research has demonstrated that families living with mental illness, HIV/AIDS and other health conditions have experienced stigma by association overtly, as well as via the internalisation of publicly held stigmatised views, otherwise known as affiliate stigma. It has been demonstrated that families living with or supporting a family member with chronic and/or persistent illness experience significant impact and that stigma often adds to this impact. The internalisation of stigma has been shown to contribute to greater psychological distress and lowered self-esteem. Moreover, those affected may feel compelled to conceal information about their situation. This can result in greater stress and social withdrawal, which in turn may constrain social support networks. Public stigma can also lead to social exclusion on an interpersonal or structural level, leading to social disadvantage and hindered life chances. Moreover, structural discrimination may perpetuate stigma by promoting negative images and attitudes toward devalued and minority groups.

Throughout the paper I highlighted that drug dependency is a moralised domain and consequently drug users are a highly stigmatised population. Given what is known about the way stigma impacts on the lives of individuals and their families in other domains, there is a conspicuous absence of literature

available to understand how substance users are affected by stigma and whether families experience stigma by association due to their relative's drug problem. Therefore, there is a clear need to address this lack of research which may be met by an exploratory study. An exploratory study relating to stigma among family of AOD users would allow an investigation of stigma experiences specific to this population, as well as the way this impacts families. A study of this nature is important as we know that stigma occurs, but we do not know how it happens toward this population. By gaining this understanding, surveys may be designed to carry out quantitative studies on large samples to find out the prevalence and severity of stigma among families of AOD users. This in turn may inform government policy makers and support services in providing targeted responses to assist this population.

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Stigma by Association Among Families of Alcohol and Other Drug Users: An Interpretative

Phenomenological Study

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Abstract

Alcohol and other drug (AOD) users are highly stigmatised. Research in other areas suggests

stigma occurs by association. Family members are particularly susceptible. Using an

interpretative phenomenological approach, a diverse range of family members of AOD users in

Western Australia (N = 12) were interviewed to investigate associative stigma. Findings

reflected stigma was experienced by perceiving and internalising negative views of others;

through the overt actions of others; and by structural discrimination. Families managed stigma

by concealing information, selectively disclosing or finding ways to project a more positive

impression of the family. Psychological distress resulting from stigma was common.

Participants felt stigma could be reduced by increasing public education, improving access to

treatment and support services, and normalising the issue within the community. This study

informs how services might be tailored to assist these families.

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Stigma by Association Among Families of Alcohol and Other Drug Users: An Interpretative

Phenomenological Study

INTRODUCTION

Alcohol and other drug (AOD) use is a highly moralised and stigmatised domain (Room, 2005). Some people perceive AOD users to be self-indulgent, weak-willed and responsible for their health predicament (Room, 2005; Semple, Grant & Patterson, 2005; Treloar & Holt, 2006; Tindall, Foster & Cook, 2010). Stereotypes of unpredictability and dangerousness promote social exclusion, via interpersonal experiences of social rejection and also at macro-social levels through structural discrimination (Link & Phelan, 2001). This can lead to physical and mental health problems and social disadvantage (Goffman, 1963; Major & O'Brien, 2005; Link & Phelan, 2001).

Stigma has been defined as a "deeply discrediting" attribute (Goffman, 1963, p.3) devaluing individuals in the eyes of others. This can be a perceived blemish of character, applied typically to those deviating from societal norms such as AOD users (Goffman, 1963; Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984). Stigma occurs within a situational social context, as it is not the attribute itself that stigmatises, but the way in which it is perceived and evaluated by others (Goffman, 1963).

Social cognitive processes such as social categorisation underpin stigma, where groups are compared based on collectively endorsed representations (Corrigan & Watson, 2002). Stigma occurs when groups are downwardly compared and this is often emotionally motivated by causal ascriptions (Weiner, 1986). Research findings also suggest that stigma can serve a social function, such as the enforcement of social norms (Phelan, Link & Dovidio, 2008). In this regard, the stigmatisation of AOD users may be viewed by some as justifiable (Phelan et al., 2008). However, it has also been argued that marginalisation and stigmatisation of AOD populations may be the main reasons for the largely unresolved social problems surrounding problematic AOD use (Treloar & Holt, 2006).

The devaluation of stigmatised individuals can extend to others by virtue of their association. In his seminal writings on stigma, Goffman referred to this as "courtesy stigma" (p. 30). Others have referred to this phenomenon as associative stigma (Mehta & Farina, 1988) or secondary stigma

(Ogunmefun, Gilbert & Schatz, 2011). Studies have found that individuals choosing to associate with stigmatised others were perceived as having the same stereotyped traits and therefore were equally denigrated (Neuberg, Smith, Hoffman & Russell, 1994; Pryor, Reeder & Munroe, 2012). Other studies have shown individuals working amongst stigmatised individuals can be discredited by providing services to groups seen by others as undeserving (Gray, 2010).

Family members are highly susceptible to stigma by association, due to the enduring nature of familial relationships (Pryor, Reeder & Monroe, 2012), biography and heredity (Mehta & Farina, 1988), as well as proximity (Goffman, 1963). Stereotypes of blame, shame and contamination (Corrigan & Miller, 2004; Corrigan et al., 2006) underpin beliefs that families are responsible for their relative's condition. This may contribute to family stigma. Research has shown families living with stigmatised conditions such as mental illness (Phelan, Bromet & Link, 1998), HIV/AIDS (Bogart, Cowgill, Kennedy, Ryan, Murphy, Elijah & Schuster, 2008) and other health conditions (Werner & Heinik, 2008) have experienced stigma by association.

EXISTING LITERATURE

Despite the recognition of the high level of stigmatisation toward AOD users and a growing body of evidence that family stigma occurs among other stigmatised groups, there has been little research on the stigmatisation of families of AOD users. Corrigan, Miller and Watson (2006) surveyed a large population sample ($N = 968$) to ascertain views toward family members with a relative who had one of three illnesses; emphysema, mental illness or drug dependence. Using vignettes to discern attitudes toward various different family members, including parents, spouses, siblings and children, they found that families of drug dependent individuals were the most harshly judged, as they were perceived as being blameworthy for the onset of illness.

Other studies have used vignettes to assess public attitudes toward associates of stigmatised individuals. Mehta and Farina (1988) used six hypothetical stigmatised identities, one of which was alcoholism, to investigate associative stigma. A mixed gender college sample ($N = 120$) was asked to respond to how they thought this condition would impact on a fellow student's life. It was found that

respondents believed a parent's alcoholism was likely to create more difficulties for their children than other stigmas.

Biegel, Ishler, Katz and Johnson (2013) used surveys to measure the impact of stigma on caregiver burden for carers of substance users with a comorbid mental illness. They examined subjective burden stemming from factors of stigma, worry and displeasure among caregivers. They found stigma contributed to subjective burden. However, the results of the study were limited as the sample comprised mainly African-American women and also the experiences related specifically to caring for a substance user engaging in treatment (Biegel et al., 2013).

Finally, Barton (1991) used a qualitative sociological framework to examine the experiences of 20 parents managing role-formation and adaptation following the discovery of their adolescent's problem drug use. Parents reported difficulty adjusting to a new social identity and feeling discredited by authorities and community systems. Barton concluded that parents require help obtaining referrals for treatment programs, interventions that assist families as systems and support to prevent parents' assuming responsibility for their child's decision to use drugs.

These studies demonstrate that stigma occurs toward AOD users and their families. However, no studies have examined stigma from the perspectives of a diverse range of family members of AOD users to understand how stigma is experienced, so we have little understanding of how this impacts on these families. Furthermore, the literature holds no information from the perspective of families as to how stigma may be reduced within the AOD field. Researchers need such information if they are to develop valid survey instruments to quantitatively investigate the prevalence and severity of stigma in this population, and to inform policy makers what supports are needed and what measures could be taken to reduce stigma for this population. Therefore, the current study was designed to address this gap in the literature by posing three research questions: How do families of AOD users conceptualise stigma? What are the experiences of these families in terms of stigma and how has this impacted on families? And finally, what are families' views on how stigma may be reduced in the AOD field?

METHODS

METHODOLOGY

I used an interpretative phenomenological approach in this study, which is informed by a social constructionist epistemology (Crotty, 1996). Grounded in traditions of phenomenology, hermeneutics and idiography (Smith, 2011), interpretative phenomenology seeks to uncover and convey a deep understanding of the meanings underpinning everyday life experiences (Smith & Osborn, 2003). This approach allows the interviewee to explore and convey their experiences in a flexible and detailed way (Smith, 2011). A two-stage process takes place as each informant provides his or her personal account, which is then interpreted by the researcher. Smith (2011) has referred to this as a double hermeneutic process "whereby the researcher is trying to make sense of the participant making sense of what is happening to them" (p. 10). The broad aim was to reveal the experiences of families of AOD users and the underlying meanings attached to these experiences.

ETHICS

Ethical approval was granted via the Human Ethics Committee of Edith Cowan University (ECU), Western Australia. Data will be stored at ECU and may be accessed in future for legitimate research purposes. However, no identifying information will be attached in order to maintain the anonymity of the participants. An information letter providing details of the study was provided to all participants prior to being interviewed and an opportunity for questions was provided prior to interview commencement. Verbal consent was obtained from each participant; with an emphasis that interviews could be ceased at the request of the interviewee should they have become distressed or wish to withdraw from the study. This did not occur and all participants completed full interviews. Participants were offered details for counselling services if necessary, however, this was not required by any interviewees. Participants were also assured their anonymity would be maintained and names have been changed for de-identification purposes.

SAMPLING

Twelve adult family members were purposively sampled with the assistance of the Drug and Alcohol Office of Western Australian and Western Australian Networks of Alcohol and Other Drug Agencies. Information was posted on an intranet site to AOD agencies and hard copy flyers were distributed to some metropolitan agencies. Eight participants were obtained through this process. One participant was from a regional area and eleven resided in the Perth area. Snowball sampling was used to reach four participants (Taylor & Bogdan, 1988). Participants were Caucasian and comprised ten women and two men (seven mothers, one father, two siblings, one adult child and one spouse). Three participants were aged between 30 and 40, two between 41 and 60 and seven were over 60 (*Mdn* = 60). One participant spoke about experiences as a mother and also as a sibling of an AOD user. One mother had only two sons and both were AOD users, so her experiences related to both sons. One interview was conducted with both parents of an AOD using son.

DATA COLLECTION

I collected data via in-depth, semi-structured interviews that were audio-recorded. To build rapport while also obtaining background information, interviews commenced with: "Tell me a little bit more about your family situation" followed by prompts to elicit sufficient detail to identify the relationship to the user, the underlying nature of the AOD problem, and how long it had been impacting on the participant. I asked participants if others were aware of the AOD problem in their family and this was followed with a broad open question of "Tell me everything about how that is for you". The focus of the inquiry was to understand how others related to family members when they were aware of an AOD problem. This broad non-leading approach was taken to uncover experiences of stigma without suggesting that topic to the participant. Nonetheless, two participants were aware the research was related to stigma because they were working in the AOD field.

Following this broad inquiry, I asked participants to conceptualise stigma (although all participants described stigmatisation, some had not used the term stigma). If participants were unaware of the construct, a definition was provided from the Australian English Dictionary, being "a distinguishing

mark; *esp*[ecially] of disgrace" (p. 521). This was required on two occasions. Opportunity was given to reflect on this definition before further questioning was pursued.

Throughout the interviews I used a process of inductive interviewing, allowing the participants to provide detailed accounts of their experiences and interpretations of events without being led (Dickson, Knussen & Flowers, 2007). This process involves prompt-questions to obtain greater depth (experiential detail) and breadth (scope of topics), such as "tell me more about that", "how do you make sense of that?", and "give me some examples of how that has happened". Participants were given opportunity to provide additional information at the close of interview. They were also encouraged to contact the researcher post-interview should they wish to make further contributions. I requested permission to contact participants at a later date in order to verify meaning once themes had been established. Thematic saturation was reached when no new major insights were gained (Taylor & Bogdan, 1998).

FINDINGS AND INTERPRETATIONS

DATA ANALYSIS

Interviews were transcribed verbatim and reflective notes were taken to help keep track of initial thoughts to assist in the interpretation process (Taylor & Bogdan, 1998). A thematic analysis involved transcripts being read and re-read to gain an overall sense of the data. A journal was kept and after reading, notes were made of biases and questions (Taylor & Bogdan, 1998). With each reading a more thorough and active process was undertaken, identifying and highlighting significant concepts, sentences and statements. Notes were also taken in a right hand margin. Emergent and recurrent patterns were identified and data extracted to exemplify these patterns. Data descriptions were formulated moving between deductive and inductive positions, noting the emergence of unanticipated issues as well as conceptualising issues by taking a theoretical stance. This allows extant psychological theory to be augmented or challenged as the analysis progresses (Eatough, Smith & Shaw, 2006). Data reduction involved developing a list of labels and significant statements which were applied to these labels, forming clusters and a thematic map was created from these clusters. This revealed four overarching themes; (1) stigma conceptualised; (2) stigma experiences; (3) managing stigma; and (4) reducing stigma. For interpretive rigour, ideas were triangulated by discussing themes with a supervisor and with three peers

researching stigma in other domains. Member checking was carried out by contacting participants post interview, once themes had been identified. Although attempts were made to speak with all participants, only six were able to be contacted. The themes were discussed and the quotes used to reflect themes were shared for clarification. All participants consulted agreed themes were congruent with intended meaning.

THEMATIC TABLE

Table 1: Themes and subthemes to emerge from key informant study of stigma among family members of alcohol and other drug users.

Theme	Subtheme
Conceptualisation of Stigma	No subthemes
Stigma Experiences	Perceived Stigma
	Affiliate Stigma
	Associative Stigma
	Structural Stigma
Managing Stigma	Concealment
	Disclosure
	Impression Management
Reducing Stigma	No subthemes

STIGMA CONCEPTUALISED

Stigma was difficult for some participants to define, whereas others had a firm understanding. Numerous themes emerged in terms of the way stigma was conceptualised and these included a sense of deviation from normality, social distancing, weakness of character and personal failure. There was also a description of being contaminated due to the behaviours of others in the family, as well as a sense that stigma results from beliefs about causality and personal responsibility for the problem. Some participants expressed stigma as a sense of others' awareness of a deviance from normality, which accords with classic definitions of stigma (Goffman, 1963; Link & Phelan, 2001). Kristen, whose two sons are AOD users, provided her conceptualisation:

"Well stigma is, it's just the fact that they're not like you, and if they're not like you, they're not normal.".

Bonnie, whose daughter and brother were both AOD users, admitted finding it difficult to articulate and yet provided an eloquent conceptualisation involving a deviation from normality:

"I know what it is, but it's hard to put it into words. Stigma is when a person is vilified by the general community, for being different, for being subnormal or being a bad person."

There was also an understanding that weakness of character is an aspect of stigma. This is an underlying principle of stigma according to the literature (Goffman, 1963). As described by Fran, a mother whose son is an AOD user:

"I just think people are blinkered and they've got their view, whatever their view might be, of what a drug addict is, and I don't think they can see beyond that, that there's probably reasons why that person's like that; that they're not just a weak character, that there's other issues. And that's how I assume most people view things; [they] just think 'oh, it's easy, you can just stop, you've only got to have a bit of willpower".

Social distancing is a hallmark of stigma (Angermeyer & Dietrich, 2005) and this related to another conception of stigma conveyed by Tracey, whose son is an AOD user:

"Stigma is I suppose people thinking, or put us in that situation like being treated as outcasts or whatever, [people thinking] 'oh my god, don't go near them, their son's a drug addict'..".

One participant conceptualised stigma in terms of associative stigma (Mehta & Farina, 1988). As stated by Dana, whose mother is an AOD user:

"I suppose it's those labels and judgements really that come with it, that you're going to be tarred with the same brush really. That perhaps you're either going to, you'll be predisposed to be a drinker or a drug user, or you're going to have particular behavioural problems because of your past, because of how you were brought up."

Dana's comments accord with Corrigan & Miller's (2004) family stigma stereotype of contamination, where it is perceived families become contaminated by other family members' behaviour. Vance, the brother of a drug user, conceptualised stigma by relating how his brother might be viewed as

having caused his own problem. He recognised that AOD users might be seen as less worthy of help, a factor which has been reflected in other stigma related research (Weiner, Perry & Magnusson, 1998):

> *"The stigma about [my brother] is that people will brush him to the side more so than look at the problem and try and deal with it, because really to them it just needs to go in the too hard basket. And he got himself into it, so he can bloody well get himself out of it, sort of thing, and that's a lot of people's view, and that's a shame".* (Vance)

Although some participants did not use the term and found the concept difficult to verbalise, other related terms such as "*judgement*" were used to convey experiences of stigma. Participants commonly related feeling negatively evaluated (judged) by others because of their family member's AOD use, or otherwise experiencing overt judgements such as others making disparaging comments about their parenting styles.

The terms and definitions used by participants to communicate their conceptualisation of stigma highlighted the broad ways stigma is understood. Overall, the way in which stigma was defined by participants was as a sense of being perceived as different, labelled, abnormal, weak, contaminated, outcast and also as less worthy of help.

STIGMA EXPERIENCES

There were a range of stigma type experiences shared by participants, which could be broken into four subcategories, being perceived stigma, affiliate stigma, associative stigma and structural stigma.

PERCEIVED STIGMA

Corrigan, Watson and Barr (2006) referred to perceived stigma as stereotype awareness. Participants described an awareness of the way AOD users are perceived in the community and how this might impact on them as a family member. For example, Tracey relayed her awareness of prevailing attitudes towards AOD users as being unworthy:

> *"..the view that people who took drugs were just worthless and not worth thinking about, and I guess I was a bit concerned that people would start to think about my son, that he was just somebody that wasn't worthy of trust.. not worthy of caring about.."*

Others had a sense that people would assume an AOD problem indicated dysfunction within the family, as illustrated by Dana:

"You know, there's so much stigma and shame that goes along with being a parent of a child who's using drugs or alcohol. You know, all that stuff around, 'oh, what went on in their family'."

This was also conveyed by Kathy, whose sister was an AOD user:

"The thing that really I found quite confronting was that my parents couldn't accept it and didn't feel that they could talk to anyone about it, because it was the big shame. You know, because we had 'one of those' in the family".

Some participants were aware of others' views because of conversations around drug use and overhearing others' opinions, as detailed by Kristen:

"There are people out there who are very, very judgemental and they just label people. And when you hear that you don't feel you can say 'hang on a minute, my son is a drug addict. Actually, I do have two sons that are drug addicts'. I mean, you wonder how they would react to you. They'd probably just give you a wide berth and talk about you in the coffee room."

An awareness of negative labelling was reported by numerous participants, recognising terms such as 'junkie' and 'druggy'. This was outlined by Jodie:

"Yeah, it's a funny thing; like they'll say 'oh, he's a druggie'. Well my son's a druggie too.. They're talking to you and like, they forget about you..."

This awareness of how others viewed AOD underpinned a sense of exclusion and a reluctance to be open about their situation. One way of avoiding these types of views was to choose social networks where people felt they were less likely to be judged. However, in working situations this was clearly not possible. One important insight expressed by a participant was an awareness of why she might be feeling ashamed and she suggested this might stem from previously held stigmatised views.

As illustrated by Kristen:

> *"And then about the shame, I just think because, I don't know, maybe I have a stigma about drug use, because you think to yourself well why have I suddenly taken on this shame, and then you think is it because my perceptions of a person who uses drugs is shameful anyway?"*

This awareness of how she felt about AOD users before this became an issue in her family made Kristen acutely aware of how others might be thinking about her. It could also lead to a heightened sensitivity in detecting stigma, which has been documented in other stigmatised populations (Angermeyer, Schulze & Dietrich, 2003).

Given that most participants described a sense of shame or blame arising from their family members' AOD use, there is suggestion there was some level of endorsement of these stereotypes (Corrigan & Watson, 2002). This leads to the second type of stigma experience, affiliate stigma.

AFFILIATE STIGMA

Affiliate stigma, or self-stigma, refers to the internalisation of negative societal views (Mak & Cheung, 2008). A sense of blame, shame and guilt was commonly referred to by participants. This indicated external views of responsibility had been internalised and correlates with other studies of affiliate stigma (Chou, Pu, Lee, Lin & Kröger, 2009; Mak & Cheung, 2008, 2012; Werner & Shulman, 2013). Kristen outlined her feelings of blame, as follows:

> *"The guilt is that you've done something wrong... what had we done that must have made this happen?"*.

Feelings of blame also stemmed from concern about what others might think and a sense of being a bad parent was commonly described. Tracey described this feeling:

> *"..its thinking 'oh my god, what have I done wrong?'; you know, 'how come?'; 'I must have been a bad parent somewhere along the line, this must be my fault'. I guess that's kind of a little bit of the shame as well or the, 'oh my god, what will people think?'"*

A sense of failure was also expressed, particularly from parents' perspectives, but also siblings, as described by Kathy:

> *"And especially their stance that they failed, you know, they failed to, to pull her through.*

But, certainly, they felt it.. What didn't we do, what could've we have done, why didn't it work, how could this have happened?"

A sense of failure was also felt from the perspective of a spouse. Michelle, whose ex-husband was an AOD user described this experience:

"I think it's more the shame and the guilt, that because I had such a good career prior to meeting my husband, the shame that I'd gone downhill, I'd basically degraded.. it wasn't like we were going up, we were going down so, when you're telling people you're going up and this is how good life is, but really behind the scenes it's not so rosy, it's kind of embarrassing and you don't want people to know."

The sense of failure, shame and guilt described here suggests there was a belief that having an AOD user in the family led to a lowering of social status and of reputation damage. The feeling that the behaviour of an AOD family member impacted on the reputation of participants and had brought shame on the family was a point commonly raised.

Internalising feelings of shame and blame had a distressing impact on family members and this was described as leading to a sense of isolation and sadness. There were also feelings of not belonging and of being damaged, which was described by Bonnie:

"Embarrassment, the feeling that nobody else has ever gone through that before, that you're experiencing something that nobody else has ever been experiencing before. That you're odd, different; .. The feeling that you're somehow inadequate, or damaged. I think those are the feelings that make you want to curl up and die really."

Dana also described a sense of feeling damaged:

"So it was always this sense of feeling oh god, they think I'm damaged goods, kind of thing. And I was quite aware of keeping as a secret from them for a long time."

ASSOCIATIVE STIGMA

Stigma was experienced in various forms once others became aware of an AOD problem in the family. Often this came from other family members and experiences ranged from parenting skills being criticised to being totally shunned by other family members. Kristen shared her experience of a sister and brother-in-law severing ties when they learnt of her sons' drug use:

"..it was a shock .. we've really been shunned by them. So ..when my other brother-in-law was trying to get us all together they made it quite clear they didn't wish to see us.. I did feel that was stigmatising me, because that was judging me, and really they had no right to judge me on what my sons had done; that was like punishing me because of what they've done."

Vance described an experience of being excluded from a significant family event because of his brother's AOD use.

"Yeah, the rest of the family's pretty much dumped him. You know, and me being his brother, I also find that we don't get invited to any family things anymore....I get associated, I sort of get brought down the same level sort of thing.."

Another common experience was being shunned by friends, which was distressing for some participants. Dana shared an experience from her childhood, due to growing up with an AOD using mother:

"..when parents realised about my mum's alcohol use then they were a lot more wary about their kids hanging around me and certainly coming to the house, which is completely understandable; but very hurtful at the same time for me. Obviously, people stopped coming to the house and it was sort of excuses that were being made ...I did get this sense of feeling like [my friend's] mother was really very suspicious of me and I don't know in what sense but it's just that kind of, wary of me and not really sure whether she wanted her daughter hanging around me or not and that kind of thing".

Another participant had a contrasting experience, where his friends were accepting of his brother's drug use issues, showing concern and offering assistance, as outlined by Vance:

"Yeah, just they're concerned. They haven't shunned me and they wouldn't. That's just from being mates and knowing what it's like out there."

One participant did not necessarily view the rejection of friends as a negative experience, in that she felt it helped her to discern the genuineness of those within her social realm. Michelle's thoughts were:

"For me I was dealing with enough at the time anyway, so it was just like the care factor wasn't there. To me it was a realisation that they're not really friends I guess, and you're able to let go of them easy."

Associative stigma became a prominent issue when it was more salient and difficult to conceal, such as residing in a small country town or among neighbours who had close ties with the family.

Overall, there was a sense that others did not understand the issue and this was often accompanied with a lack of empathy.   This became particularly difficult if there were other stigmatising markers, as was illustrated by Bonnie:

"A lot of people asked me, 'why isn't she married? Why has she got all these children by different men? Why is she out in the street late at night? Why is she taking drugs? Why is she doing this and that?'. And there's no way I could answer that because she's her own person."

Dana also spoke of a lack of understanding:

"I think for many people they've not necessarily had somebody close to them really struggle with their mental health and alcohol or substance misuse, then it's hard for them to really know, actually just how complicated it is. You know, I think for some people they think all they have to do is take a magic wand or go into rehab and click your fingers and that's it."

Stigma by association experiences were also felt by some participants in their working environment.   One experience was detailed by Jodie.   She felt as though her son's AOD problem contributed to her being terminated from her employment:

"..they thought well who do I get rid of; me with a problem son..".

STRUCTURAL STIGMA

The experience of structural stigma was described in a variety of ways by participants and difficulty in accessing services was commonly spoken about. This was not dissimilar to findings among families of mentally ill patients (Angermeyer et al., 2003). Family members felt they had to undertake somewhat onerous searches to find the support they needed. Waiting lists for counselling and programs were also a prominent issue. This was expressed by Kristen:

"You know and then they tell you that you've got to wait. You know there's always this waiting and it seems, when you're going through this it seems huge the length of time. You just want to get to someone that day and talk to somebody.".

Sue also shared her experience with respect to treatment waiting lists:

"Where does your child go? If your child needs to go to a Psychiatrist or Psychologist, there's such a massive waiting list."

Others mentioned the stigma of the media with relation to AOD issues, such as by Fran:

".. I think there's so much comes that you hear in the media and that; like every time there's a break-in, there'll be drug addicts, it'll be kids after money for drugs, it's just reported all the time isn't it".

Vance also discussed the influence of the media, as follows*:*

"[People have] seen on the television and the news, you know read in the paper, six heroin overdoses and this horrible drug and what it does to people and families and this that; I think that's where people draw their information from."

There was a sense from participants that the way AOD use is perceived by the broader public and the establishment is likely to influence the way funds are distributed. Kathy expressed her disappointment that a program to provide opiate users with an antagonist drug (naloxone) was not implemented, as she believed the program could have saved her sister's life.

".. they just trialled whether they were handing it out to peers, so the peers actually had the Narcan, so if they had someone drop they could actually inject them.. but then I think when they started talking about something like that and something was squashed about it ..and then started thinking [gasp] you mean, like someone could have saved her, but they didn't want to give them the money?"

Another point made by Vance was the exclusive nature of rehabilitation services, in his understanding there is an expectation for total abstinence. Vance's brother had made an attempt to address his heroin use, but was not able to remain within the treatment centre if he wished to continue smoking cigarettes.

"We stuck him in the [detoxification centre] and unfortunately, I think he would have stuck with it, but he didn't because he couldn't smoke in there. He just couldn't handle it. Now, in a way, I don't blame him; that would have been hard.. I think if he'd stayed there and done the program that might have actually been a turning point for him". (Vance)

MANAGING STIGMA

Three subthemes of concealment, disclosure and impression management were found in relation to the management of stigma.

CONCEALMENT

In their model of stigma, Jones and colleagues (1984) suggested concealable stigmas are hidden from others as long as possible and findings of the current study corresponded with this model. Families in this study withheld information from other family members, which at times led to family disharmony. There was both function and dysfunction in concealing, in that it was seen as a functional way of managing stigma and protecting significant others by some participants. Other family members chose to withdraw from social situations to avoid conversation about their family member and to maintain their secrecy around the issue, leading to diminished quality of life. Goffman (1963) suggested this is a common way of keeping control of information about the concealed identity. Keeping the secret was difficult and often led to intrusive thoughts, as reflected by Kristen:

"I didn't want to talk to anyone, I didn't want to go out, didn't want to meet anyone. I mean if I thought I was going to run into someone I'd panic. Because I just thought they're going to ask, they're going to ask about the kids. What if they've found out? What if they've heard something? And that was all running through your head, all the time. That they might have heard something; what if they've seen the police here? What if their son's in the police force?..."

Participants also described difficulties in remembering what has been told to maintain a consistent story and this was an issue outlined by Pachankis (2007). There was a sense of living a constant lie, with consequences if discovered, as described by Bonnie:

"It takes a lot of energy, because you're manufacturing a perfect life to cover up a life that is so imperfect. So you're kind of trying to remember what you've told people. It's like being a compulsive liar; you've got to remember the things that you've told people so you can match up with the things you tell the next person. I kept telling people that my daughter was sick, and that she had a problem but I didn't identify what it was.. all the time I knew the people would see what was really going on... So, the perfect life that I'd created in my head, because I was believing it just as much as I was hoping other people would believe it. It just all crumbled away and we were just left open to criticism of any kind."

DISCLOSURE

Disclosure was another method of managing stigma, however, this was generally done on a selective basis. Selective disclosure has been highlighted as a common means of managing a concealable stigma (Pachankis, 2007). Some participants were comfortable confiding in other family members and

friends. They found this advantageous as it provided an outlet and a means of support, consistent with other research (Cree, Kay, Tisdall & Wallace, 2004). Participants expressed that disclosing to someone after concealing for a considerable period of time brought a great sense of relief. This was expressed by Dana:

> *".. when I did disclose, finally, then it really turned everything around and I got a lot of support from school; a lot of extensions, or help or whatever it was....Just that relief for being able to talk to somebody about it, that is the biggest thing; it's just actually going 'oh god, I can talk about this and these people aren't rejecting me..' "*

Participants described experiences of disclosing to others and discovering issues in common, otherwise choosing to disclose if others revealed they had AOD issues within their family. There was a general sense that most people keep these things a secret, however, the revelation was that AOD issues among families are actually quite common. This view was expressed by most participants, either as a perception or actual experience. Debbie described an experience where she happened to meet a cousin in a shopping centre whilst in a state of distress regarding her son. Although she had not disclosed to anyone else, her cousin insisted they talk, so Debbie decided to disclose:

> *"Yes, well I was so upset and I was crying and she made me say what's going on and I had to tell. And she said don't, she said I've got a son who's been doing that, dabbling in marijuana and that. She said we have the same issues; it's not like you're on your own. So that's when she rang; she had an appointment with these drug people as well, and she thought there was one more place available. So she rang them for me and they said, yes come. So I did, and that's where my journey started".*

Not only was it a relief to disclose for some participants, but it allowed opportunity to access formal support. The benefits of formal peer support were commonly emphasised. It provided a non-judgemental space for people to communicate their issues and was seen by some participants as critical for their wellbeing, as outlined by Jodie:

> *"They've just been my lifeline really, I mean, family is there, but they don't know what you're going through ..".*

Tracey also articulated her experience of group support being a place of openness and camaraderie:

"..but what I have found is that the people that I've met have been absolutely amazing; they're all very strong.. and it's the sort of place where you can just go and talk completely openly, you can talk about your son's drug addiction, you can talk about your son's legal issues and because every single one of them there is probably in exactly the same situation as you; they've all been through it, or going through it, so it's kind of a sense of belonging I guess, a kind of a sense of, almost like coming home.   Yeah, so it's really quite powerful."

It was the sense of others understanding their plight that made a real difference to participants, as some found the experience of disclosing to family and friends more isolating. There was a common feeling that if others had not been through a similar situation, they did not have the necessary insight to provide the support that was needed. Often this led to a sense of frustration, particularly if others tried to solve the problem for them, or otherwise tried to make sense of a problem they were unable to make sense of themselves. This was illustrated by Kristen:

"Well, I have a friend, a close friend; .. she knew after about a year... And, but her reaction; it's funny how people react because when I actually told her, she just looked at me and she said, 'well how could that have happened, because our kids, our kids went to the same schools, did the same things, how can yours do that?' ..I said, 'why did you say that?', and she said 'well I'm trying to work it out'. [I said] 'But why are you doing that? I'm trying to tell you what's happened in my life and you're trying to analyse why it's happened to my son and not happened to your son'. But she couldn't understand why I felt the way I did... I said well I don't want you to sit there and analyse what happened to my son and not your son; I want you to be supportive."

Dana also outlined the importance of understanding the problem:

"what I've probably found difficult is when people get into trying to solve problems, you know they, or they just don't really understand the magnitude of the problem."

Overall, choosing whether or not to disclose was conveyed as a relatively taxing exercise, as there was much consideration given to when and with whom disclosure should take place. There was a sense of apprehension with regard to the unpredictable nature of responses from others and there was often ambivalence about whether to disclose, particularly in work situations. On the other hand, ability to make selective disclosure seemed to provide participants with some sense of power and control over their situation, which was important given other aspects of the problem felt out of their control.

IMPRESSION MANAGEMENT

Another means of managing stigma that presented more as a latent theme was impression management. Some family members emphasised the good qualities of their family member, possibly as a

means of directing attention away from their AOD use or other issues. Voysey (1972) suggested that public appearances of family members may be seen as reflecting the state of the family and also the competence of parents, which may underpin this type of impression management. As outlined by Daphne with regard to her son:

> "Because where he stays at the moment, he does the cleaning, he has the kitchen and it's spotless. He likes to be dressed nice and neat and that kind of thing. Like he's not a slob, as such. I mean he does smoke cigarettes, but he likes to present himself nicely and things like that. He was always very generous, I might have said that earlier on, but he was always very generous. When he came to Christmas and stuff like that, he always brought like very kind of expensive presents. But he was very thoughtful, very, very thoughtful".

This was also voiced by Gavin:

> "You see, this is partly because he's our son, yes, but it's also very, very true, he is and if he didn't take it [cannabis], he's such a gentle, loving kid um and as we said earlier very, very genuine and the people that he moves around are all smoking marijuana and getting it from different people and .. they're not the same type as him at all".

Other family members described disguising the AOD use by calling it something else and this was a technique employed by family members in other stigmatised populations (Angermeyer et al., 2003). For example, Kathy described the situation with her parents when talking about her sister's AOD issues:

> "Mum and Dad, fairly early on I tried to link them in [to counselling], but that was at the stage when they didn't really want to talk about it because … she just had an issue with money really, it wasn't anything else. So it was [my sister's] 'money' issue."

Some families spoke about making excuses for their family members' AOD use. For one participant it was that her son had a physical disability. It was felt that when speaking to others about the AOD use, she would suggest it was related to him coping with his disability. It seemed this may justify his use or make it more acceptable to others. As outlined by Fran:

> "..but, I think we, when (Gavin) and I speak about it, we use it as an excuse, we use, you know, he's got [a physical disability]. He takes drugs, but it's because; we did it to [him]."

This was also an example where two stigmatising conditions are present and several participants described situations where their family member had more than one stigma. For example some family members had an AOD issue in conjunction with a mental health problem. One participant preferred telling others her child had a mental illness rather than an AOD problem, as illustrated by this quote:

Debbie: "I've put it; the last time that my son was put in hospital, we were at friends' for dinner and we were called to the hospital when we were there so we had to say .. just a nervous breakdown."

Researcher: "So you feel more comfortable with them thinking it's a psychiatric issue than a drug problem?"

Debbie: "Yes, exactly, that's exactly right and I don't know whether I'm wrong in not telling them."

The theory of downward comparison holds that subjective wellbeing can be improved by comparing with less fortunate others and this can occur either passively or actively (Wills, 1981). This was indicated by Michelle who described a perception she was more 'normal' than her AOD using ex-spouse:

"... they could see that you know this wife looks so normal, what's with this addict, you know."

There were other comments from participants where a downward comparison was made, either with other types of drug use or other discreditable behaviours, such as offending. This was illuminated in a quote by parents Gavin and Fran:

Gavin: ".. one of the things I always, I can hear myself saying it, you know, I say that he's taking marijuana and very often at the end of the conversation I say 'but luckily it is only marijuana', which you say because I think it could be heroin or you know, acid or one of the really awful things; I don't know whether that's the right attitude to take, I mean marijuana can be pretty, it is certainly with [our son] pretty addictive, you know, I don't know why I say that."

This was also reflected by Vance when talking about his brother:

"I think a junkie is a different classification; I think that's really someone who is down and out. You see [my brother] doesn't,. ..he won't you know steal, he won't prostitute or anything like that, to get his money for drugs; he'll sell drugs to make his own cash to buy them or he'll use what money he's worked for or Centrelink or whatever to buy his drugs. He won't steal or rob people or anything like that, which is always good.."

Although possibly not driven by a conscious sense of impression management, there were some actions taken that may have assisted in reducing stigma or improving one's image in the eyes of others, such as becoming a volunteer for AOD related services. Numerous family members, particularly parents, became involved in formal support services after learning of their family member's AOD problem. This

may have demonstrated to others that they were trying to make positive changes (Jones et al., 1984), but also may have been a means of redeeming some sense of control over their situation.

REDUCING STIGMA

There were numerous ways in which participants believed stigma toward people affected by AOD might be reduced, but responses predominantly centred on providing education to make people more aware of AOD related issues; improving availability and quality of care for people seeking treatment, for both users and families; and also normalising the problem. First, participants suggested education was a means of providing more information about AOD issues as a way of demystifying the problems experienced by AOD users and their families. Education is one approach being used to reduce stigma towards mental illness (Corrigan, 2004). Bonnie compared the issue to other areas where public opinion seems to have changed through information provision and education:

> *"More information for the public [is needed]. As in autism; I have a grandson who is autistic and people used to be terrified of autism, but now that it's being promoted as an illness or a state of mind within the community and people know more about it, it's not so scary and I think if people know more about addiction and alcoholism and all that kind of stuff; at the moment it's all just kind of held in little pockets, like in AA and in the recovery centres, and in the withdrawal centres. Professional people know about it, but not the people in the street. And when people hear the words alcoholic or drug addict, they think [gasp]".*

Others suggested that it was ensuring there was education, but more importantly that this was accessible for people as highlighted by Tracey:

> *"Well I would've said a lot more education, but I guess the truth of the matter is there is a lot of education out there. Um, I think it's just maybe that people don't know where to go to get it. Because I didn't, like there was nothing, I'd never seen anything anywhere.."*

Advertising in local newspapers was also suggested. One participant thought this was a way information could be provided on a broad scale:

> *"I again would probably refer to the more advertising of drug use and basically making people aware of an addict and what addiction is. I think that even if they had a mini booklet in the newspaper or something that people could just read up on it because I don't think everybody's aware of it. They hear of drugs and they just think, oh that's disgusting but they've never really*

picked up [information], to read about how people become addicted because of years of abuse or whatever it may be.." (Michelle)

Other participants suggested public forums may be a means of informing people, as well as reducing the sense that people are on their own when dealing with AOD issues, as illustrated by this quote:

"I think there could be more public forums. Definitely. In the local community, not just in the city, in the local areas ..It would just make people aware that it's everywhere; it's not just an isolated incident if there's drug taking. It's everywhere in the community and it should probably be, you know like, if they talk about it more people will know and it wouldn't be such a big deal for people if their son got in trouble or daughter got in trouble". (Debbie)

The idea of public forums was a common suggestion. Some participants had been to such forums in the past. There were suggestions on how these forums may be improved and better focussed, such as including speakers who talk about real life experiences. This was felt to have a significant impact in helping people to understand the nature of AOD issues. This type of contact is a means of breaking down barriers and is one of the ways mental illness stigma has been tackled (Corrigan, 2004). Kristen highlighted what she thought was needed:

".. we need more public forums and not ones that you have to pay to go to. It's got to be a public forum where parents can just go along and listen to people share their stories. There's nothing like that; we don't need morning tea and afternoon tea and a lunch provided... People don't want that; they want to be able to go along to a public thing where they can just sit and listen."

Some participants suggested that advertising and challenging negative media messages relating to drug use may assist in reducing stigma, whilst recognising the inherent difficulties with changing public opinion. This has been referred to as a means of protest in other anti-stigma campaigns (Corrigan, 2004). As suggested by Fran:

"I think that you'd have to have massive advertising campaigns somehow or other. I don't know how you could possibly do it, to make people realise that there's another side...".

Numerous participants suggested using high profile stories to emphasise the breadth of the issue as well as creating some sense of normality around families experiencing AOD issues, as was reflected by Kristen:

"Well, it's funny because every time, like when Ben Cousins [sportsperson] was going through the drug thing.. because of the personality he was I think people started to think oh, you know, this is a talented young man, he's got this huge future ahead of him and yet he's succumbed to drugs and that's been the falling down of him. And you could see that more people, some people started to think you know, maybe there's something in this, maybe we should be a bit more sympathetic.."

There was also ambivalence about efforts to change social attitudes toward drug use. This was conveyed by Kathy, who lost her sister to AOD use, but was also concerned any alleviation of social attitudes could cause harm, as illustrated in this quote:

"I think it's about what is socially acceptable. You know, I could say I'm addicted to horses; ... but that's socially acceptable.. .. it's not so acceptable to be crazy about the wonderful Ms H [heroin]. I think those things and you know how do we change that, and do we want to change that? You know quite frankly, I don't know what I would do if my children chose to have that love affair that my sister had. Yeah, that would be something else totally. And you know seeing the pain that my parents went through, it's up there with the pain of losing my sister."

DISCUSSION

In this paper, the stigma experiences of families of AOD users were presented, as well as the way families conceptualise stigma and how they feel stigma may be reduced. The research adds to the existing body of knowledge regarding stigma toward family members. It provides an insight to the experiences of families of AOD users in relation to stigma and the impact on those families. This is the first qualitative study to have captured and reported on the experiences of this population in this way.

Definitions of stigma provided in this paper suggest this is a social process where individuals or groups are devalued by others for perceived negative attributes. This study identified that some family members were familiar with the term stigma, while others were not. Irrespective of familiarity with the term, there was a common sense of being judged because of their family member's AOD problem. Participants described stigma as being perceived as deviant, of having weak character and by noting the desire of others to distance themselves. These definitions align with classic formulations and conceptual models of stigma (Goffman, 1963; Corrigan & Watson, 2002; Link & Phelan, 2001). Therefore it is clear participants had an awareness of what stigma is and how this applies to them as family members of an AOD user.

The experience of stigma manifested in numerous ways. This included perceptions of stigma, internalising negative external views, actual enacted stigma experiences and stigma via structural discrimination. These findings echoed the experiences of families in other studies reporting on stigma by association (Angermeyer et al., 2003; Wahl & Harman, 1989). Participants perceived they would be stigmatised based on their awareness of prevailing attitudes toward AOD users and the likelihood they would be held to blame for their family member's problems.

This perception is not without foundation, given findings from previous studies that parents and spouses are held to blame by others for their family member's drug problem (Corrigan et al., 2006). Corrigan and Miller (2004) suggested stereotypes such as incompetence may also play a role in stigmatisation of families. This corresponds with the current findings where family members, particularly parents, felt as though they had erred in raising their children and were exposed to external views challenging their parenting skills and decisions. Public perceptions of causality such as these can have a significant impact, noting that causal attributions often lead to others having less sympathy and withholding help (Weiner et al., 1998).

Although suppressing information may spare individuals from the negative evaluations of others, concealing a stigma can come with significant costs. As reported in other studies (Mwinituo, Mill, Stevens, Demi & Ayres, 2006), the act of covering up described by respondents led to a greater sense of isolation and less access to support. Psychological distress arose from the vigilance needed to maintain the secret and avoid being discovered. These types of issues added to existing concerns about the family predicament.

A critical aspect for the wellbeing of the respondents in the current study was their involvement with formal peer support networks and this reflected findings in other studies (Barton, 1991). This was mainly due to the mixed responses received after disclosing. It was frustrating when others did not understand their plight. It was emphasised that having people to talk to without judgement and who understood the issue was critical to being able to cope. This has also been highlighted in other studies (Angermeyer et al., 2003). Respondents had clear ideas on how stigma toward this population may be reduced. These included broadening public education; reducing treatment waiting times; challenging

negative media images; and normalising the issue within the community. It was important to respondents that information was readily accessible and easy to find. Having access to real stories from those impacted by AOD use was emphasised, as it was felt this type of information was very useful and served to normalise the issue.

LIMITATIONS

There were some limitations to this study. First, all respondents were Caucasian. This could be partly due to the use of snowball sampling methods. Therefore, it remains unknown whether family stigma experiences or conceptualisations differ among other ethnic and racial groups, but further research may address such questions. Second, several family members in this study had more than one stigma, such as mental illness, physical disability or a forensic background. Therefore, there could be an overlap in the stigma experiences of respondents and it is difficult to distinguish the specific cause of the stigma. That said, these issues often go hand in hand with drug use and regardless of whether another stigma was involved, it is well documented that AOD is a behaviour that leads to stigma (Room, 2005) and also that often multi-level stigma is experienced (Tindal et al., 2010). Therefore, at least some stigma toward families would stem specifically from their family member's AOD use. Finally, most participants in the study were mothers of drug using sons and the experiences of this demographic may be limited in terms of overall scope to understand impact on the whole range of family members.

CONCLUSION

The purpose of this study was to explore the experiences of family members to ascertain how they perceived and experienced stigma resulting from their family member's AOD use. The present study builds on existing literature relating to associative stigma among families. It was found that families had an awareness of being judged by others and there were many ways they experienced stigma. This had a considerable emotional impact and added to the burden of coping with the AOD problem.

In terms of implications for policy makers and support services, the present findings emphasise the importance of access to formal peer support networks and services for families managing an AOD problem. Having an environment to share experiences, as well as obtain and give support was an important means for families to regain a sense of control, worthiness and acceptance. Moreover, the

importance of information being available on a broader scale so that services and treatment are readily accessible is paramount, as well as implementing change on a macro social level to avoid further isolating affected families.

Implementing change by first understanding the severity and prevalence of stigma among this population could be achieved with additional research. Based on the information gathered in the current study, a survey instrument could be designed to conduct a larger scale quantitative study that would enable these factors to be measured. Such a study might further assist policy makers and support services in gaining a better understanding of services needed and how these services may be targeted to reach this population.

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Appendix A

Guidelines for Contributions by Authors

<u>Journal of Drug Issues</u>

PREPARATION

Manuscripts should not exceed 30 pages of text. Prepare text in Times New Roman 11 point type. Manuscripts should be double spaced, including references. Do not use automatic endnote function in your word processing program. Endnote marks in the text should simply be superscripted numbers, and notes should be typed separately at the end of the text. For reference on style, see the *Publication Manual of the American Psychological Association,* 6th ed. Sample articles formatted according to JDI's style guidelines may be viewed <u>here</u>. Manuscripts will not be accepted until they are formatted correctly.

FOR INTERNATIONAL AUTHORS: ENGLISH LANGUAGE REFINEMENT AND EDITING

JDI receives many submissions from authors that are non native English speakers. Unfortunately, many of these manuscripts must be rejected outright because they are difficult for reviewers to understand. We strongly encourage authors for whom English is a second language to seek help from professional editing services before submitting their manuscripts, which will greatly increase chances of acceptance. For useful resources and information, please see <u><http://www.sagepub.com/journalgateway/engLang.htm></u>.

ABSTRACTS AND BIOGRAPHICAL SKETCHES

An abstract not to exceed 150 words and biographical sketches not to exceed 50 words for each author should be provided.

RUNNING HEAD

Submit a short running title of no more than 55 characters, including spaces.

HEADINGS

First level headings should be bold and aligned left. Second-level headings should be italicized and aligned left. Third-level headings should be italicized and indented:

FIRST-LEVEL HEADING
SECOND-LEVEL HEADING
    THIRD-LEVEL HEADING

REFERENCE LIST

The reference list should be formatted according to American Psychological Association (APA) and JDI style guidelines. All references should be complete. JDI's style requires including the names of all authors, full titles of periodicals and books, and volume and page numbers.

TABLES AND FIGURES

Tables should be prepared in Times New Roman 10 point type. Table notes should be prepared in

Times New Roman 9 point type. A location in the text for each table and figure should be indicated (e.g., "Table 1 about here"), and tables should appear after the reference list.

REVIEW
To facilitate anonymous review, only the title of the article should appear on the front page. Names, affiliations, complete mailing addresses, e-mail addresses, phone numbers, and fax numbers of all authors should be included on a separate cover page. Authors should keep a copy of their manuscripts.

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(NB The Research Paper in this document will be submitted for publication with the Table of Themes omitted in order to meet the prescribed page limit).

Appendix B

Research Flyer

RESEARCH PARTICIPANTS WANTED!

Does someone in your family have a problem with alcohol and/or other drugs?

That can make life very stressful for the whole family. One area of potential stress (but also potential support) is how other people (friends, work mates, service providers) relate to you when they know you have a person in your family with a substance use problem. That is an important issue that has not been well researched.

We are keen to hear about your experiences and how you think others perceive you and relate to you when they know you have drug use problems in your family.

($25 will be provided to participants)

If you are interested in being a part of this research
or would like to make further inquiries,
please contact
Olivia Marshall
Mobile: █████████
or email
ojohnson@our.ecu.edu.au.

Appendix C

Information Letter

Does someone in your family have a problem with alcohol and/or other drugs? I am looking into the experiences of families in this situation, particularly with view to understanding how people relate to family members when they know they have a relative with a drug problem and some of the stresses that may come with this.

My name is Olivia Marshall and I am undertaking this research as part of the requirements of a Psychology (Honours) degree at Edith Cowan University. If you would like to participate in this study, please contact me at ojohnson@our.ecu.edu.au or on 0487 450 476. It will involve an interview of around sixty minutes to take place at a time and place that suits you. Questions will be asked relating to your experiences as a family member of someone who has a drug problem with a focus on how you feel others around you, including friends, workmates and service providers, relate to you when they know about the drug use problems in your family. An audio recording will be made of the interview and will be destroyed once the details have been transcribed for analysis. You will be given a $25 voucher per hour for your participation in the interview (provided by the WA Drug and Alcohol Office), however, please be aware your participation is voluntary and you can withdraw from the study at any time without explanation. Any data collected from you will be then be destroyed. If you find the interview distressing in any way, details of telephone counselling options will be provided to you.

The study will be following strict ethical guidelines in accordance with the Edith Cowan University Human Research Ethics Committee. Your confidentiality will be maintained and measures taken to ensure you cannot be identified by providing information for this project. Once the information you have provided has been analysed, it will be de-identified (names changed) and then used in a research thesis. All of the data that is collected will be securely stored at Edith Cowan University. You may obtain a copy of the report upon request at the completion of the research. You should also be aware the research may be published in reports, journals or conference papers. Your de-identified data may also be used by future researchers to verify findings of the current study.

If you have any questions or require any further information about this research project, please contact Olivia Marshall on 0487 450476, or alternatively my Supervisor, Dr Greg Dear on 0438 985289.

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Research Ethics Officer
Edith Cowan University
270 Joondalup Drive
JOONDALUP WA 6027
Phone: (08) 6304 2170
Email: research.ethics@ecu.edu.au
Thank you for your interest and valuable time.

Olivia Marshall

Email: ojohnson@our.ecu.edu.au

Appendix D

Consent Form

Details of Consent

(To be read to participants and audio-recorded)

I have been provided with a copy of the Information Letter explaining the research project and have understood the details provided. I have been given the opportunity to ask questions and feel satisfied my questions have been answered accordingly. I understand that if I have any further questions I can contact the research team (Olivia Marshall or Dr Greg Dear).

I understand that participation will involve an approximate sixty minute interview which will be audio-recorded. I understand the information I provide will remain confidential and my identity will be protected. I am aware the research details may be published in reports, journals and conference papers but that my confidentiality will be maintained. The data collected for the purposes of this research may be used in further approved research projects provided my name and any other identifying information is removed.

I understand that I can withdraw from the research project at any time without explanation or penalty and that if I choose to, no information I have provided will be included in the study.

I freely agree to participate in the project.

Appendix E

Interview Schedule

The interviewer will introduce themself and thank participants for taking part in the research. Background information is to be requested in order to build rapport and gain some understanding of the extent of the problem. Reserve questions should be used if the participant does not mention stigma in the first instance. The interview should close with an opportunity for the participant to add further information.

1. What is your relationship to your family member you've come to talk about?

2. Tell me a little more about your situation.

3. Apart from the service providers who have put me in touch with you, do other people outside your family know about your circumstances?

   a. Tell me everything about how that is.

4. Reserve questions

   a. Tell me, what is your understanding is of stigma?

   b. Are there any experiences you've had where you have felt stigmatised?

   c. How does that come to happen?

5. What sort of things do you think could be changed to make this any better?

Probing questions:

- Explain to me..?

- Help me understand…?

- Tell more about…?

- Expand that out/Elaborate on

- How do you make sense of that?

- Where do you sit in relation to that?

Appendix F

Thematic Table

Table 1

Themes and subthemes to emerge from key informant study of stigma among family members of alcohol and other drug users.

Theme	Subtheme
Conceptualisation of Stigma	No subthemes
Stigma Experiences	Perceived Stigma
	Affiliate Stigma
	Associative Stigma
	Structural Stigma
Managing Stigma	Concealment
	Disclosure
	Impression Management
Reducing Stigma	No subthemes

Appendix G

Journal Extracts

Post interview reflections

Participant 1

The first participant contacted me soon after the flyers were distributed as she worked in the AOD industry. The interview was conducted by phone and although I was feeling relatively confident beforehand, as I felt I had adequately prepared and rehearsed the questions in my mind, it was harder than I expected it was going to be. The challenge I found was to focus on the content and grant due attention to what was being said, whilst still maintaining some structure and thinking about the way I was prompting and asking questions. It was important for rapport building and ensuring the participant felt comfortable to have a natural flow to the questions and I had to really think about this. Given the emotional content of the interview, this was even more challenging. The experience shared by this participant related to her sister who had died 18 months beforehand of a heroin overdose, so there was a particular need to be sensitive, whilst still adhering to the task at hand. The interview emphasised that these are real stories of heartache and grief I will need to ensure I do the best I can to do these stories justice.

Participant 2

I met with participant 2 at a community meeting centre. I used the experience of the first interview to try and hone my skills and I felt the interview went smoother than the first, particularly in the way I used my prompt questions. This participant came to talk about her son who used methamphetamines and this had been a problem for around two years. It was interesting that she talked about having changed her attitude towards drugs since this became an issue in the family and that others such as her mother had done the same, whereas her mother had spoken very disparagingly about drug users in the past. This participant had found such great strength and support from the formal groups she had accessed that she had decided to volunteer herself and felt this may also change her career path; it had changed her outlook significantly. However, she also emphasised that it was difficult for her to find help in the first instance, because she just did not have any idea where to start looking. This was a real issue for her, particularly as the places she sought help, such as through a GP, were relatively unsuccessful.

Participants 3 (& 4)

This participant contacted me to discuss her son who had a long term issue with marijuana use. When I arrived at her home for the interview her husband was also present, so I was asked if he could also participate. As he was another family member, I agreed, but in hindsight this perhaps was not the best idea as it made it difficult to isolate the experiences of each individual as they saw it, without influencing

one another. Nevertheless, some interesting insights were provided, noting that stigma was conceptualised differently than the first participant. There was a lot of information that related to family burden, which is a separate issue from stigma, but this seems to overlap a lot. It is also interesting that stigma was described as stemming from other family members in this interview, whereas this was not the case in the first interview. Something that also stood out for me was that it seemed that it was easier for this couple, the husband in particular, to talk about their son's disability with others rather than his drug use. Does this suggest they see drug use as being more stigmatising and less acceptable than physical disability? Does this relate back to what I have been reading about responsibility being a significant factor in the way a stigma is perceived?

It was emphasised during this interview that an important part of coping with their son's AOD issue was contact with a peer support group, which was initially accessed around ten years ago. Although the group is no longer formal, the women involved keep in regular contact. I was grateful this participant added that others within the group may be interested in participating and that my details would be passed on.

Participant 5

This participant agreed to participate in the research after being contacted by participant 3. She spoke about her only two sons who were drug users. The experiences she shared were profound. She had mixed experiences from other family members. Some shunned her when they found out. She chose to hide information from her sister despite having a close relationship with her and they didn't speak for over 12 months as a result. So there were real sacrifices made to keep things a secret. When her sister did find out, she couldn't understand why she hadn't been told and was actually very supportive. In reflection, it seems like a real minefield to navigate, in terms of who and when to tell about an issue such as this. I noticed this participant had a real agenda in terms of wanting to facilitate change. It was important to her that someone listened to the issues impacting on family members of AOD users, indicating she felt as though she had not been listened to in the past. A real emphasis was placed on the waiting lists for treatment. This reminds me of something that I've read, about the stigma continuing for families as long as the issue is there. I can see then, why families would be keen for facilities to be available when their family member indicates they are ready for change and the sense of urgency underpinning this. Another thing that stood out to me in this interview is the sense of grief this participant talked about, in that she felt as though she had lost her sons because they would never have a 'normal' life, so it was like this part of her life had died and she was in mourning. But the paradox was that her sons are still here and the issues are ongoing, so it seemed like a process of never-ending grief. This participant also suggested she would contact other women in the group to gauge their interest and pass on my details.

Participant 6

This participant was also accessed by snowball sampling. The interview was conducted at her home. She was a quietly spoken, but very eager to assist. She had a different way of presenting information than the

other two participants who had come from her group. I sensed that she was very unsure of herself and throughout the interview it became apparent that she felt she had come a long way in this regard since learning of her son's drug issue. She had said that initially she was too embarrassed to speak with anyone outside of the immediate family and it was clear this took a real impact on her life. The sense of relief that she spoke about when realising by chance that her cousin had a similar issue was quite palpable. This chance encounter led her to being connected with the group, which she described as being where her 'journey' started. I thought this was an interesting way to talk about it, as it seemed to be place a great significance on this aspect of her life. I am starting to sense this from the parents I've spoken with; that this turning point in their lives came from not only learning about their child's drug use, but also connecting with others facing the same problem. When talking about her connection with the other ladies in the group, this participant's whole mood seemed to lift and she communicated in a more confident way. I did note though that this participant was quite suggestible and although I was asking questions, it was clear on some occasions she felt I was giving advice. It was interesting that she interpreted this in this way and I felt it important to clarify that I was not suggesting, but asking about her thoughts and experiences. I also found it interesting that this participant claimed she had not had any stigma experiences, but yet described changing her behaviour and concealing information from others in order to avoid judgement. This indicates that although there may not be experiences of overt stigma, there is still something going on for her behaviour to be altered or information to be withheld.

Participant 7

This participant was also involved in the group of other women I have interviewed. She spoke to me during a break from work, so I was very grateful that she had used this time to speak with me. She spoke about her son who had been a drug user for around 15 years. She was a single parent and I noted that her experiences were similar to the other parents I have spoken with, however, that she has to carry the entire burden herself. There were also other issues of criminality stemming from her son's drug use and she had recently been threatened by him which was a great cause of distress for her. Her experiences indicated that she was entirely fatigued by trying to manage her son's issues. This was highlighted particularly by her accounts that she felt unsupported by authorities such as the police. Although a lot of the issues discussed were similar as had been referred to by other participants, there was an emphasis during this interview that much of the issue lies with not addressing the issues underpinning drug use. This participant thought a harder line should be taken in providing treatment for users and drew an interesting comparison with people suffering with anorexia. She suggested that measures are taken to force feed people with this illness and felt this approach should be taken to treatment for drug users, citing that this is an illness which is just as serious and life threatening. I thought this was a really interesting perspective. There was an overriding sense from this interview though, that she never knew when this problem was going to end and that it seemed to her that it may never end. There was a real sense of hopelessness and I felt myself really hoping that something changes in this participant's situation to give her some hope.

Participant 8

This participant was also reached via snowball sampling as she is a part of the group of ladies I've been speaking with. Again, this participant spoke about her son who has been a drug user for some time. He also had a mental health issue. This was another interview where no real stigma experiences were felt, but unlike other participants, there did not seem to be any real accounts of concealing information or adverse reactions from others. This was an interesting difference. I noted though that when I asked about stigma and how others related to this participant when they knew about the AOD issue in her family, she would quickly digress and talk about her son's qualities; about his employment, his generosity, his neat presentation and generally his likeability. I came away from the interview feeling as though I had not asked the right questions and had not prompted correctly to get the information I needed.

After this interview, I kept thinking about how this participant said she has not had any stigma experiences, and also that throughout the interview she preferred to emphasise her son's good features; is there a tie between these two things? Optimism? Wanting to maintain a good identity? Either some sort of conscious or unconscious process or mechanism to avoid stigma being taken on board or tarnishing image of oneself or her son? I need to do more reading about this; and check articles already read.

Subsequently, I had a brief peer discussion to talk about this interview, and this helped to clarify my thoughts.

Participant 9

The interview with this participant was conducted over the phone. She talked about experiences of her mother as an AOD user. She spoke about the pressure of the situation coupled with having to maintain the secrets and lies, leading to anxiety and depression. This compounded issues because of the inability to share, for fear of rejection and fear of other negative consequences such as being removed from the home.

A lot of it the discussion was about perception; what will they think of me? What will happen if I tell someone? There was an underlying sense that reactions will be negative – where does this come from? There was an emphasis on help being constructive and empowering, rather than others trying to impose solutions; or otherwise trying to solve the problem rather than just listening. A couple of statements that I think were important but I'm not quite sure where they fit in; about kids having to hide their parents' drug use issues, not having support and having something dire happen as a consequence; at best not succeeding, at worst suiciding

This interview gave the perspective from a child and this participant was able to provide clear suggestions in terms of what strategies may assist in not only providing support for young people in this situation, but also to reduce stigma (educating the community). Strong patterns in terms of benefits of disclosure and damage as well as the difficulties of concealing.

I felt this interview went well and flowed smoothly and I feel as though my skills are improving with each interview.

Participant 10

This participant was interviewed in his home. He spoke about his younger brother using heroin. In terms of stigma experiences, family shunning was the main stigma experienced. This participant seemed to have quite an acute sense of associative stigma; that is, being avoided and excluded because of his brother's drug use and other family members viewing him as being the same as his brother in this regard, despite him not being a drug user.

He did not have a clear understanding of the stigma concept, but when explained, understood the concepts of social rejection and devaluation because of certain behaviours. He indicated his awareness that this is something which affects his brother and in turn which may affect him because of his association.

With regard to reducing stigma this participant suggested promoting awareness; providing information, although also had an understanding that people have to be interested or want to be provided with this information, that it cannot be forced upon them. He said that this is due to caring. He also spoke about a sense of understanding from others throughout the interview when they had had some contact with or some familiarity with the concept of drug use, such as friends who have used or otherwise an aunt who was a nurse therefore had some medical knowledge. It seems that the underlying message here was that it is perhaps ignorance to some degree that causes people to act negatively toward drug users (stigma).

Participant 11

This participant was interviewed in her home and spoke about her husband who is a methamphetamine user; they have since separated and he is presently in gaol. They have been married for five years; together for ten.

She described different experiences of stigma. Initially she discussed concealing or withholding information, keeping secrets from friends, feeling embarrassed and ashamed and the sense of likelihood she would be devalued if others knew about the problem. It seems since she has separated from her husband, she has been able to distance herself from his behaviour and emphasised this throughout; that she is not a drug user, not 'that type of person', doesn't make choices like that and doesn't want to be seen in that way; described her husband as 'the addict' and there a distinct sense of wanting to distance herself – it seems this has been a critical factor in terms of her healing and being able to move on; underlying suggestion it is also to avoid stigma and being 'tarred with the same brush'. Since making this mind shift (and life change) she has become comfortable talking about her situation with others and it seems there is a sense of triumph that goes with this; that she has survived this experience, that she was able to rise above it. She perceives herself as being able to help others in a similar situation because of this triumph. Perhaps it is more palatable for her self-image to be seen as a survivor, than a victim or someone associated with

what she termed herself as being disgraceful behaviour (when referring to drug use). Is this indicative of not being able to change the person's behaviour, therefore changing the association so as to avoid the negative label?

This participant could not define stigma; even when a definition was provided, she did not seem to fully grasp the concept and indicated her own stigmatisation toward others - her partner for his drug use and other parents that her son goes to school with; she indicated they seemed to be of a lower socio-economic status? Downward comparisons – is this another way of elevating sense of self?

In terms of reducing stigma this participant emphasised the importance of making resources more available to people in order to obtain appropriate support. She also talked about raising awareness regarding drug issues and normalising this in a sense, in terms of addiction being a common community problem that can apply not only to drugs, but to other areas as well such as with self-regulation with food; she also used porn as an example.

Participant 12

This participant was interviewed in her home. She spoke about both her daughter and her brother. Her daughter was a heroin user and her brother (now deceased) used alcohol. She described and articulated very clear experiences of social rejection, a sense of her daughter's reputation (as a drug user) impacting on her; all within the context of being in a small town. She described a sense of frustration at not being able to avoid this kind of negative labelling and stereotyping. She had an acute sense of being stigmatised due to her daughter's drug use.

Consistent with other experiences, she talked about feeling the need to lie and conceal information and this taking a lot of energy; a very stressful process.

She also outlined the difficulty with getting assistance because the major and accessible agencies were inclined to focus mainly on the children and this meant neglecting the needs of others affected in the family, including her and her daughter. She described a sense of shutting down and not wanting to be a part of the world; social avoidance and withdrawing from normal life.

I feel as though there are themes coming through here in terms of others not wanting to know, because it was too hard for them. No support because others wanted to avoid the situation - is this also because they wanted to avoid stigma? Perhaps getting too close might have also placed them in the same basket? I need to relate this back to my readings.

An interesting new idea was put forward, regarding drug use and addiction in that it may have links back to propaganda movies in the 40's demonising drug use and painting a picture of drug users as 'sex crazed' and 'drug fiends'. No one else has mentioned this or had such insight as to where these attitudes may come from.

I'm starting to get strong sense (throughout, not just with this participant) that the concealability of the stigma plays a large role. Once it becomes difficult to conceal, or noticeable to others, it becomes more difficult to manage. This is particularly difficult in a small town where one loses their anonymity and behaviours become apparent to others.