THE UNIVERSITY OF HULL

Experiences of participants of support groups, in relation to substance misuse and shame

being a Thesis submitted for the Degree of Doctor of Clinical Psychology

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by

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Overview

Support groups are commonly found to be empowering and constructive of the mental health of those attending, not least within the arena of substance misuse. Shame on the other hand is an emotion that is detrimental to the social functioning and well-being of many participants of such groups. The conjunction of these contrasting foci, are explored in the following research portfolio.

This is comprised of three sections. The first is a systematic literature review, collating literature in the field of support groups and shame or *internalised stigma*; a close relation. The literature is synthesised and presented in the form of themes arising from the information extracted, with reference to the quality of studies selected. The review concludes by delineating the overarching benefit of groups for those who may suffer shame or internalised stigma.

Part two describes an empirical study in which the experiences of parents of illicit substance misusers are examined. This is done so qualitatively, with reference to parents' understanding of the role that shame and stigma may play in their lives and experiences of the support group they attend. Outcomes of thematic analyses of interviews with participants are presented, and major themes are discussed. Benefits for parents of attending the support group is highlighted as one of the main themes.

The final section of the portfolio consists of the appendices which support Sections One and Two, including a brief reflective summary of the research process from the author's perspective.

Contents

List of tables.

Systematic literature review

Empirical Study

Word Counts (excluding abstracts, tables, qualitative data, references and appendices)

Systematic Literature review: 6, 851

Empirical study: 6, 938 (11, 674 including qualitative data).

Total portfolio: 13, 789

Part One

A systematic review of group support and attendees experiences of shame.

This paper is written in the format ready for submission to the Journal of Clinical Psychology. Appendix A contains the guidelines for authors.

A systematic review of group support and attendees experiences of shame.

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Abstract

The aims of the review were to synthesise information regarding how shame and internalised stigma is experienced in conjunction with support groups. Literature was systematically searched electronically and manually. The resulting data was grouped together in themes. Five major themes were identified: shame or internalised stigma in relation to the utilisation or attendance of support groups, the de-shaming and the de-stigmatising impact of support groups, support groups as a forum in which to discuss issues of shame, and a smaller theme of the shaming impact of support groups. Populations which experience shame and internalised stigma are likely to avoid the social exposure which support groups facilitate. Accessibility could therefore be improved for shame-prone groups.

Social support has become a particular area of interest for research over the past two decades. Simultaneously, the sphere of mental health has seen a rise in the number of support groups (providing social support; Katz & Bender, 1976), attended by people with a wide variety of problems (Roberts & Salem, 1999).

Erosion of community cohesion is thought to be one reason for this increase in utilisation of support groups (Jacobs & Goodman, 1989; Murray, 1996). Growth in the number of groups for those with mental health problems may also be a result of deinstitutionalisation and the subsequent Mental Health Consumer Movement (MHCM) from which consumer-led groups evolved (Davidson et al, 1999). Patients being discharged into the community are thought to need more of a bridge into supportive social networks than that provided by formal mental health treatment (Davidson et al 1999 again). Group interventions may be more empowering for this group, than individual interventions (Wilson, Flanagan & Rynders, 1999; Barrera, 1986).

The term ‘support groups’, is inherently complicated. Though it has been disputed to be often erroneously synonymised with mutual aid, or self-help (Farriz-Kurtz, 1997), the distinctions are complicated by a lack of clarity and consensus between professionals, organisations and peer-led community groups (Galinsky & Schopler, 1995).

There are many branches of support group, constituted in varying ways. For example, mutual support which is facilitated by organised groups is different from naturally occurring mutual support, which may not be intentional. Additionally, larger, more established self-help group networks also often contain an inherent world view or spirituality which is an integral element of its approach. Examples of these networks are Alcoholics Anonymous, other 12 step programmes and ‘GROW’, the latter of which is an international mutual help organisation for people with mental health problems, founded by former sufferers (Oakes, 2008; Shrikhandi, Dermatis & Gelanter; 2008 Finn & Bishop, 2006). The core world view or spirituality inherent in these groups may be used as a *cognitive antidote* to the collective problem the group has been formed for support with. In this context, the term cognitive antidote refers to therapeutic properties the world view may employ, in ameliorating the cognitive impact of the collective problem shared by the group (Kennedy & Humphreys, 1994).

For the purposes of this study, the term ‘support group’ will encompass any group which meets the five fundamental attributes of the support group, as defined by Katz and Bender (1976). This definition has been endorsed by the World Health Organisation (Van Ommeren, M; Saxena, S, & Saraceno, B., 2005) among many others, (e.g. Adamsen & Rasmussen, 2003). These attributes are: being a small group with face to face interaction, an emphasis on personal participation, voluntary attendance, an acknowledged purpose for coming together such as to solve or help individuals cope with a problem, and the provision of emotional support (Katz & Bender, 1976).

It is important to distinguish the ‘support group’ from the therapeutic group, which is usually directed from a therapeutic modality, and has specific psycho-therapeutic aims (Yalom, 2005; Forsyth, 2004). Though in reality there is considerable overlap between therapeutic groups and support groups, the underlying origins, motivations and leadership of groups on the two ends of this spectrum are indicative of social and psychological considerations which render them very separate (Burns & Taylor, 1998; Bor & Tilling, 1991).

In general, though support groups are beneficial for those with many types and levels of severity of psychiatric and mental health problems, (e.g. Bracke, Christiaens & Verhaeghe, 2008; Mercer & King, 1994; Tudor, 1996) they are apparently regarded as more appropriate than group therapy for helping those with non-psychopathological problems, for example, the bereaved (Pietila, 2002).

Support groups are widely recognised as beneficial for the general well-being of those who attend, as well as in improving specific symptomatology (e.g. Hinrichsen, Revenson, & Shinn, 1985; Humphreys, Mankowski, Moos, & Finney, 1999; Humphreys & Noke, 1997 & Rathner, Bonsch, Maurer, Walter & Sollner, 1993; Hogan et al, 2002). They have been considered by a number of authors to be more appropriate than engaging in a ‘cure’ approach for people with chronic mental health problems (Mercer & King, 1994; Tudor, 1996). In this population, helping others can mean building self-esteem and self-efficacy (Bracke, Christiaens & Verhaeghe, 2008). Helping others can increase feelings of competence (Reissman, 1965; Barrera, 1986) and a sense of being important to another (Taylor & Turner, 2001).

The concept of stigma is broadly described as 'a mark or sign of disgrace or discredit, regarded as impressed on or carried by a person or thing' (Brown, 1993)[1]. This is an important phenomenon to consider in relation to support groups, because it has been observed that support groups can reduce a sense of isolation and stigma for their participants (Maton, 1988; Maton & Salem 1995; Kingree & Thompson, 2000). In particular, those who experience stigma can find helping others a useful coping strategy for dealing with their own feelings of perceived stigmatisation, which can be facilitated in support groups (Loewenstein et al, 2008; Burns & Taylor, 1998).

Seeking group support has been described as a task-focussed coping strategy for stigmatised individuals (Lazarus & Folkman, 1984). The MHCM endorse support groups because they can provide peer role models, and are consistent with conceptualisations of 'recovery', which is defined as a process of individuals learning to live with their limitations, whilst re-building a sense of purpose, agency and self-identity (Davidson et al, 1999; Davidson & Strauss, 1992).

In health research, those who suffer diseases or conditions considered stigmatising or 'embarrassing' have been found more likely to attend support groups than those whose problems are more socially acceptable (Davidson, Pennebaker & Dickerson, 2000; Burns & Taylor, 1998). For example, AIDS patients were found to be 250 times more likely to participate in groups than hypertension patients (Davidson, Pennebaker & Dickerson,

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[1] Stigma is a multi-faceted concept, which can be enacted by others in the form of mistreatment or even discrimination as a result of the individual's stigmatized status; perceived by the individual as being enacted or believed in by others, or developed within an individual toward themselves (Link & Phelan, 2001). Among many negative effects of stigma, it is highly associated with the decrement of self-esteem (Corrigan, 1998; Van Brakel, 2006; Corrigan, Watson & Barr, 2006).

2000). At the same time, stigma has been documented as a barrier for those in need of care, both in seeking support for (Verhaeghe, Bracke, & Bruynooghe, 2008; Byrne, 1997; Link et al, 2001) and adhering to medication (Sirey et al, 2001) for mental health problems. Computer-mediated support groups have been found to be particularly accessible for stigmatised populations, due to the anonymity and protection from stigmatising cues they can provide (Wright, 2000a; Galagher, Sproull & Kiesler, 1998).

Some research suggests that support groups have the potential to damage self-esteem by reinforcing participants' identity as members of a deviant or stigmatized group (Coates and Winston, 1983; Seale, 2002). It has also been found that social comparison using social cues (likely to occur in group support interventions; Hogan et al, 2002) can lead to negative affect (Buunk et al, 1990).

An association between experiencing stigma and feeling shame has been documented (Lewis, 1998; Cook, 1983; Turner, Dofny & Dutka, 1994; Wehmeyer, 1994; Link et al 2002; Elison, 2006; Kulick, 1998, Link et al, 2004, Luoma et al, 2007; Scheff, 1998; Byrne, 1997; 2001). Stigma is a multi-faceted concept (Link & Phelan, 2001), and internalised stigma is found to be an aspect of stigma closely associated with shame (Ritsher, Otilingham & Gragales, 2003; Byrne, 2001; Corrigan & Penn, 1999), though it can occur in the absence of shame (King et al, 2007). This has sometimes been labelled 'self-stigma' (Corrigan, 1998; Ritscher, Otilingham, & Grajales, 2003; Link & Phelan, 2001). Feeling different and ashamed has been found to be a consequence of perceived stigmatisation in a study involving people with mental health problems (Link et al 2002).

Both stigma and shame have also been found to be relatively strongly related to coping mechanisms involving secrecy, social withdrawal and feelings of low-self esteem and depression (e.g. Link et al, 2001; Link 2002; Byrne, 2001). Though there is no commonly agreed definition of shame (Gilbert & Proctor, 2006), it has been described as experiencing one’s external and internal worlds as hostile and persecuting (Gilbert, 1997; Gilbert et al, 1994; Lewis, 2003). It is widely recognised in research that shame can have many detrimental effects on mental health (e.g. Lindsay-Hartz, de Rivera, & Mascolo, 1995; Aslund et al, 2007; Gilbert, 2003).

Despite the well-established negative effects of shame on mental health (e.g. Lindsay-Hartz, de Rivera, & Mascolo, 1995; Orth, Berking & Burkhardt, 2006) and the strong (Kingree & Thompson, 2000), but apparently ambiguous association between support group attendance and stigmatisation, which is associated with shame (Link et al 2002; Elison, 2006; Kulick, 1998, Link et al, 2004, Luoma et al, 2007; Scheff, 1998), little research in which shame and face-to-face group support is the primary focus, has been identified. In contrast to this, there is a wealth of literature concerning group therapy and shame, spanning several decades (e.g. Smith, 2008; Hadar, 2008; Wright, 1994; Alonso & Rutan, 1988; Horner, 1975; Gilbert & Proctor, 2006) suggesting that the group as a therapeutic modality is effective in ameliorating the effects of shame.

Support groups are very much encouraged among mental health service users (Davidson et al, 1999; Solomon, 2004) due to their demonstrated benefits for well-being and mental health in various areas (Hinrichsen, Revenson, & Shinn, 1985; Humphreys, Mankowski, Moos, & Finney, 1999; Humphreys & Noke, 1997 & Rathner, Bonsch, Maurer, Walter & Sollner, 1993; Hogan et al, 2002). Support groups have even been used in mental health services specifically as a means for de-stigmatisation (Byrne, 1997). Another benefit of support groups is that they have been documented as being more economical than therapeutic groups, since they do not usually rely on paid professionals to facilitate them (Burns & Taylor, 1998; Mataix-Cols & Marks, 2006; Zvolensky et al, 1999).

Computer-mediated support groups have been assumed to be more beneficial for stigmatised groups than face to face support groups (e.g. Wright & Bell, 2003). However, there is a lack of clarity regarding the evidence of face-to-face support groups and participant's experiences of shame, considering the established benefits of support groups for the stigmatised, and the associations between stigma and shame. This review may contribute to redressing that balance. It is also important that existing research including the experiences of shame or internalised stigma of those who attend support groups is highlighted and synthesised for clarity and accessibility, and in order to point to areas in which future investigation may be needed.

This review will attempt to systematically explore and present the evidence linking shame and attendance of support groups. The review will provide an overview of terms used to describe what is defined above as the 'support group', in order that studies using a variety of terms may be accessible. For those who run support groups, this accessibility may be particularly useful (Kyrouz, Humphreys & Loomis, 1998). The information may help to guide referral practice if disseminated amongst clinicians (support groups for those with serious mental health problems are underutilised; Davidson et al, 1999).

Review method

A systematic review of literature in group support and shame was conducted in order to provide a reliable and replicable presentation of the area. It was anticipated that the review would produce information pertaining to a broad variety of experiences involving stigma and shame. However, the basic aetiology and consequences of both shame and stigma (including internalised stigma) are consistent across experiences (Van Brakel, 2006; Gilbert, 1997), and therefore these experiences may be compared together.

Search strategy

A variety of electronic information databases were searched from March-April 2008, reflecting the related areas of health, psychology and social care encompassed by the topic of shame and group support. These were Psycharticles, PsychINFO, Medline, Scopus, Springer Link – social sciences, Ingenta Connect, and Web of Science. Publications from 1990 onwards were included, due to the changed nature of support groups and advanced understanding of shame and stigma since that time. In the early 1990s, support group researchers began to describe a new ‘self help paradigm’, in which members of support groups were viewed as a normative community, to replace the previously marginalising approach to self help and support groups as a treatment modality (e.g. Farriz-Kurtz, 1997). Computer-mediated support groups were excluded from this review in order to preserve the homogeneity of the literature in face to face support groups and shame or internalised stigma. This is due to evidence to suggest that these experiences may be different for participants of these groups, due to the anonymity which enables shame-prone or stigmatised individuals to access them, (Walther & Boyd, 2002; Wright & Bell, 2003; King & Moreggi, 1998; Wright, 2000a).

‘Internalised stigma’ was incorporated into the search terms, due to its’ close association with shame and the prevalence of stigma experienced by those who attend support groups. Including studies in internalised stigma and shame may provide evidence of how participants are affected both interpersonally and intra-personally in support groups. Perceived stigma is an important component of internalised stigma (Ritscher, Otilingham & Grajales, 2003) and is also related to shame (e.g. Corrigan, 2004). Researchers can use these terms interchangeably (Van Brakel, 2006), thus, perceived stigma was included in the search terms used.

Search terms included various combinations of ‘support group’ and some of its context specific synonyms: class, club, service, self-help, peer support, mutual aid, mutual help, mutual support, with shame, felt stigma, internalised stigma, self-stigma or perceived stigma. Many of these terms had been identified through preliminary contact with literature in the individual areas of support groups, shame and stigma, which highlighted synonyms for each, suggesting they may be in regular use in the literature. Other terms were chosen for being commonly used descriptors of human groups, and which it was believed may be utilised by researchers in the clinical field of support groups.

Publications were further acquired through bibliographic review of obtained studies, and by hand-searching journals of interest. Authors prominent in the area of group support were also identified through contact with existing literature, and contacted via email in order to request advice for locating any in-press, or published literature not already identified. One reply was received, which advised of existing published literature by the author that was believed to be relevant.

In total, 16 studies met the inclusion criteria (see Table 1; end of the review document) of which 5 were qualitative, 9 were quantitative and 2 had a mixed design. One study was a re-analysis of data from another study included. Studies which were initially thought to meet criteria, but were later excluded are detailed in Table 2 (located at the end of the review document) and reasons given.

Study selection criteria

Included studies met the following criteria, they:

1. Were concerned with support group(s), which were identified as having the 5 key attributes outlined above, as described by Katz and Bender (1979); a widely recognised criteria (e.g. Van Ommeren, M; Saxena, S, & Saraceno, B., 2005, Adamsen & Rasmussen, 2003).
2. Included shame, or perceived/internalised/self stigma, in the methodology or findings,
3. Were primary sources of qualitative, quantitative, or mixed design studies,
4. Were written in English,
5. Were empirical studies published in peer-reviewed journals.

Initially, studies were screened using titles and abstracts as a preliminary indication of satisfied inclusion criteria. The full text was later obtained either through online databases or hard copies from a public library source. Studies were then examined against criteria, and accepted if these were entirely met.

Study quality assessment

Studies were assessed for quality according to their methodological design: NICE guidelines were used for primarily qualitative studies, in order to ensure that these were chosen for the same level of rigour as by this nationally recognised scientific body (National Institute for Health and Clinical Excellence, 2007). Quantitative studies were assessed using a checklist based on the work of Jadad, Moore, Carroll, Jenkinson, Reynolds, Gavaghan & McQuay (1996), for scrutinising quantitative research quality. This is a reliable instrument, emphasising the measurement of bias in research, which was deemed to be an important issue in the subjective arena of shame. A ‘Cohen’s Kappa’ test of inter-rater reliability for quantitative studies suggested that ‘almost perfect’ (K=0.91) agreement was reached between the author and an independent rater when scrutinising the quality of studies (Landis & Koch, 1977). Studies qualifying this assessment are included in Table1, and methodological concerns are also noted.

Data extraction & synthesis

Full examination of studies against quality checklists revealed disparate quality levels between them; not all criteria were met for every study.

Considerations had to be made as to what constituted a ‘support group’, when groups were designed or led by professionals as an intervention or a therapeutic modality was involved. This highlighted the difficulty in establishing valid boundaries between classifications of ‘groups’. Where there was uncertainty, studies were considered as to whether they prioritised the core components of the support group (Katz & Bender, 1979), regardless of whether they also included components of group therapy, psycho-education, or intervention.

Studies were analysed thematically for content relating to shame or internalised stigma, and data grouped together qualitatively. Information collected from the selected literature included type of support group, participant demographics, type of psycho-social problem experienced by the group and any components of the study relating to shame or internalised stigma.

Methodological considerations

The majority of selected studies were quantitative (N=9). For two of these (Micinnes & Lewis, 2008; McCay et al, 2007), some of the key attributes of the support group (Katz & bender, 1979) were ambiguous, rendering them of questionable validity. In both, a treatment intervention for evaluation by the authors was the primary aim and purpose of the group. Therefore, though each met the fundamental criteria of a ‘support group’, it is likely that these groups lacked the participant involvement and autonomy that would otherwise occur, and contained extraneous aims which may have obstructed the natural processes that occur in support groups.

One quantitative study raised some methodological concerns: there was no mention of ethical approval, and its single measure was not described as standardised or validated (Goldstein, 2005). Its validity in the context of the study was also questionable, since the measure related to perceived stigma towards psychotherapy. None of these limitations were discussed. The generalisability of Sikkema et al.'s study (2007) may be compromised by the absence of heterosexual male subjects.

The reliability of one further quantitative study's findings is limited by its methodology. It may have been more appropriate to employ an open, qualitative methodology in order to meet its aims to 'identify the most appreciated aspects of a short term family group...' (Staerk-Buksti et al, 2006). Reliability may also be compromised in Charles, Butera-Prinzi and Perlesz study (2007) due to the fact that the families attending their family group, were concurrently undergoing individual family therapy. Furthermore, the reliability of one of their measures (the Behaviour Assessment System for Children; BASC) may have been compromised by demand characteristics displayed by children wanting to please their elders under the circumstances. This was discussed in the study.

Ethics committee approval was not reported in three qualitative, and one mixed design study, which may call into question the appropriateness of these (Dyer-Layer et al, 2004; Pietila, M, 2002; Kissman & Torres, 2004; Duane et al, 2002). One study apparently lacking ethical approval (Duane et al, 2002) contained morally dubious questions in the interview schedule described. The author’s view is that these questions may have been perceived by participants as punitive, thereby potentially impacting responses.

In two qualitative and one mixed design study, the roles of researchers in the groups were unclear, and there was a subsequent lack of consideration displayed for the potential for bias (Kissman & Torres, 2004; Dyer-Layer et al, 2004; Charles, Butera-Prinzi & Perlesz).

Potential bias in interpreting data was an especial concern in two qualitative studies (Kissman & Torres, 2004; Hlongwana & Mkhize, 2007). The first did not specify a methodology; neither did it describe the procedure of this (Kissman & Torres, 2004). Though the second described its methodology, some of the interpretations of data apparently made a significant jump from the data itself, without any discussion of this (Hlongwana & Mkhize, 2007).

Results

The results of the analysis of included studies reviewed are presented thematically below.

1. Group support utilisation and shame or internalised stigma

Goldstein’s (2005) investigation of perceived stigma toward utilisation of a peer support programme revealed that attendees perceive less stigma towards it, and to those who attend, than non-attendees. Similarly, in a study of the recently widowed, those who chose not to attend bereavement support groups (BSGs) were found to believe that those attending were less self-sufficient, indicating a stigmatising attitude towards BSGs (Levy & Derby, 1992).

J. Kingree’s study (2000) involved a residential treatment programme in which some support group attendance was mandatory. The de-stigmatising effect observed of support group attendance for Adult Children of Alcoholics (ACOAs) was non-significantly larger for those who participated in voluntary group meetings, than for those who had no choice.

2. De-shaming impact of Support groups

A qualitative exploration of a support group for incarcerated mothers revealed the cathartic value of the disclosure of shameful experiences to sympathetic peers, and how the creative expression of which enabled one mother to progress through therapeutic stages to self forgiveness (Kissman & Torres, 2004). Coping with shame and self-blame were integral to the psycho-educative programme of the group.

Family members affected by brain injury reported reduced feelings of shame after attending a multi-family support group, as well as sharing pride in achievements reached despite acquired impairments (Charles, Butera-Prinzi & Perlesz, 2007). Experiences also included ‘moving from blame to compassion’ with regard to the injuries:

> I am no longer looking to apportion blame... I no longer feel that it is my responsibility that things ended up the way they did... we did have a lot of experiences in common (the group), and I see that as very re-assuring. It helps you make sense of what is happening to you as not necessarily personal

> this group.... has given me permission not to feel like a failure, that’s something I have felt for a long time. (Charles, Butera-Prinzi & Perlesz, 2007).

Sufferers of post abortion grief (PAG) demonstrated a highly significant reduction in shame ($p<.000$) as well as PTSD symptoms ($p<.002$) after attending a spiritually-based grief group intervention in the US (Dyer-Layer, Roberts, Wild & Walters, 2004). Qualitative data revealed that validation received from others, and the facilitation of reconciliation and forgiveness with God and others was an important factor in the reduction of shame experienced by these participants.

Hansen et al (2007) demonstrated that low shame about childhood sexual abuse (CSA) experiences in participants of support groups predicted little improvement, whereas high shame about CSA predicted improvement in levels of distress and trauma symptoms, including trauma-related shame.

3. Support groups as a forum in which to discuss issues of shame and spirituality

South African HIV positive adults described in an ethnographical study by K. Hlwongwana and S. Mkhize used their support group as a forum to discuss their HIV identity and religious beliefs concerning this (Hlwongwana & Mkhize 2007). Themes of shame and self-blame emerged, in conjunction with beliefs regarding sin and punishment. Other data suggested that a diversity of views existed and were shared within the group on the subject of HIV related shame, as some participants had found less shameful ways of viewing their HIV status: “You are not infected because you misbehaved, but because god chose you”. (Hlwongwana & Mkhize, 2007, p561).

Participants also used the group as a means to activate the less shameful status of helping others: “God gave me the virus for a reason... I had to be HIV positive so that people can learn through my positive living” (Hlwongwana & Mkhize, 2007, p561).

Spirituality and shame also featured highly in the above mentioned study examining a PAG support group. In addition to the reduction of shame for attendees, over 80% reported that spirituality and their religious beliefs played a strong to very strong role in the group (Dyer-Layer, Roberts, Wild & Walters, 2004).

Pietela (2002) documented that, relatives of those who had committed suicide attending a support group, experienced shame as a stage of the grief process. They also agreed that embarrassment was a typical reaction of others concerning the suicide.

A group support setting in which parents of adolescent child sexual abuse perpetrators discussed their experiences was used by Yvonne Duane and Alan Carr (2002) as a source from which to qualitatively derive a model of the processes and experiences, in reaction to the disclosure of their son’s sexual offense. This mode highlighted shame as one of the key stages of the process. Shame was also described by M. Pietila as one of the stages of grief experienced by relatives of those who had died by suicide, extrapolated from interviews conducted with attendees about their group experience (2002).

4. De-stigmatising impact of support groups

In their multi-factoral examination of internalised stigma, Lee, Kochman & Sikkema found that support group attendance was associated with lower levels of Internalised HIV Stigma for HIV positive adults in the US (2002). Anh Nguyen and colleagues’ qualitative

Vietnamese study revealed that a self help group was found by participants to decrease felt (or perceived) stigma as well as enacted stigma, by involving family members of HIV infected mothers in educative and preconception-challenging discussions over a period of 2 ½ years (2008).

Similar psycho-educative properties were present in other studies, the aims of which included the reduction of self stigma in participants (MacInnes & Lewis, 2008; McCay, et al. 2007). However, the hypothesised reduction in self-stigmatisation by McCay et al. in young people coping with first episode schizophrenia; after attending a group programme, was not confirmed by their results (2007).

'Status based self-stigmatisation' (SBSS) in Adult children of Alcoholics (ACOAs) significantly de-creased ($p<.02$) for participants of a mutual help group (Kingree, 2000). Self stigma was also found to significantly reduce in people with serious and enduring mental health problems following attendance of a group programme designed for that purpose, using the devaluation-descrimination scale as an indicator (Link et al, 1989; Macinnes & Lewis, 2008).

5. Shaming impact of support groups

In Staerk-Buksti and colleagues' Danish investigation as to what family members found most important about a psycho-educational support group for relatives of patients suffering first episode psychosis, respondents indicated in the 'dealing with feelings of guilt and shame' subset of their questionnaire, that they did not feel that the group had particularly had an impact in this area (Staerk-Burksti et al, 2006). Some said that they did not experience these feelings, while other said that they had not realised such feelings until the end of the course.

Two parents of adolescent CSA perpetrators commented that they initially found their support group ‘personally intrusive’ (Duane et al, 2002).

Discussion

In systematically identifying and compiling existing research regarding support groups and attendees’ experiences of shame and internalised stigma, this review has collected a broad variety of literature.

This has included an array of terms used within the scope of the ‘support group’ and ‘internalised stigma’. For the former, the term most popular was ‘support group’ (Hlongwana & Mkhize, 2007; Duane et al, 2002; Kissman & Torres, 2004; Levy & Derby, 1992; Pietila, 2002; Lee, Kochman & Sikkema, 2002; Hansen et al, 2006) though other terms were ‘group programme’ (MacInnes & Lewis, 2008; Staerk-Buksti et al, 2006), ‘group intervention’ (McCay et al, 2007), ‘mutual help group’ (Kingree, 2000), ‘self-help group’ (Anh Nguyen et al, 2009), ‘peer support programme’ (Goldstein, 2005), and the more context-specific terms; ‘spiritual group intervention’ (Dyer-Layer et al, 2004) and ‘multi-family group’ (Charles, Butera-Prinzi & Perlesz, 2007). Descriptions of each of the above groups were consistent with the definition of ‘support group’ chosen to be adopted in this review (Katz & Bender, 1979).

Of the studies which included the tenet stigma over shame, only one used the term ‘internalised stigma’ (Lee, Kochman & Sikkema, 2002). Three used the synonym ‘self-stigma’ (MacInnes & Lewis, 2008; McCay et al, 2007; Kingree, 2000), two used ‘perceived stigma’ (Levy & Derby, 1992; Goldstein, 2005) and one, ‘felt stigma’ (Anh Nguyen et al, 2009). For the purposes of this study, self stigma will henceforth be termed ‘internalised stigma’.

Some studies have set out to examine the concept of shame or internalised stigma in specific populations, while others have identified these as an unexpected finding. Relatively few have set out to examine shame or internalised stigma specifically in the context of the support group.

Five major themes have been identified: shame or internalised stigma in relation to the utilisation or attendance of support groups, the de-shaming and the de-stigmatising impact of support groups, support groups as a forum in which to discuss issues of shame, and finally, a smaller theme of the shaming impact of support groups.

The overarching theme of the examined literature, is that group support has been found to be effective in ameliorating shame and internalised stigma in a wide variety of clinical and non-clinical populations (Anh Nguyen et al, 2008; Kingree, 2000; MacInnes & Lewis, 2008; Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007; Dyer-Layer et al, 2004), or its attendance correlated with lower levels of internalised stigma (Lee, Kochman & Sikkema, 2002). The latter finding was hypothesised to be related in part to having been exposed to others bearing the same stigmatised status (Lee, Kochman & Sikkema, 2002).

The success of support groups in lessening internalised stigma is thought to be a result of the psycho-educative properties of group support, building self-esteem, and in engaging those who most actively stigmatise attendees (Anh Nguyen et al, 2008), as well as providing a forum in which a consensus between participants could develop regarding beliefs and responses to internalised stigma, including the opportunity to challenge its perceived legitimacy (MacInnes & Lewis, 2008). Negative correlations of varying significance have been observed between self esteem and internalised stigma (Kingree, 2000; MacInnes & Lewis; Anh Nguyen et al, 2009), indicating that the self esteem building properties of support groups may have a positive impact on internalised stigma.

Because internalised stigma probably does not naturally reduce over time (Link et al, 1997), it is most likely that elements of group support do aid the observed de-self-stigmatisation. However, much is still unknown about how support groups help diminish internalised stigma, and what exactly these elements are (Kingree, 2000; MacInnes & Lewis, 2008; Lee, Kochman & Sikkema).

The impact of support groups in lessening the experience of shame on the whole, has been qualitatively examined (Dyer-Layer et al, 2004; Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007). In this area, meeting with others with similar experiences, social comparison and gaining a sense of universality about problems borne by participants, enabled validation, self-forgiveness and a subsequent reduction in shame (Dyer-Layer et al, 2004; Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007). Writing poetry to be shared with the group served as a catharsis for one participant for the shame associated with her incarceration and separation from her children (Kissman & Torres, 2004).

Shared spirituality has shown itself to be an important arena in which participants can find reconciliation with God, others and themselves (Kissman & Torres, 2004; Layer et al, 2004; Hlongwana & Mkhize, 2007). However, this finding may not generalise to all cultures, as these studies were undertaken principally in the US and in South Africa. Nevertheless, self forgiveness can apparently have an important role to play in reducing shame.

As well as decreasing shame, support groups can also be a forum in which to discuss issues of shame (Hlongwana & Mkhize; Charles, Butera-Prinzi & Perlesz, 2007; Kissman & Torres, 2004; Duane et al, 2002; Pietila, 2002). For some researchers, the perceived safe environment of the support group for participants has enabled them to document disclosures of shame in order to develop models or theories of specific experiences (Duane et al, 2002, Hlongwana & Mkhize, 2007; Pietila, 2002). In other studies, discussing experiences of shame has served as a catharsis for, or even helped to diminish the effects of shame itself (Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007).

However, some evidence was found to support the theory that attending support groups may reinforce negative feelings towards the self (Coates and Winston, 1983; Seale, 2002). This included an example of participants who had not realised feelings of shame until finishing a course of support group meetings (Staerk-Burksti et al, 2006), while participants of another group had found the experience ‘personally intrusive’ (Duane et al, 2002). However, the latter study may be compromised by the lack of reported ethical approval and its perceivably punitive approach to interviewing participants.

It is perhaps the experience of judgement which many who suffer shame and internalised stigma fear will ensue, should they join a support group. Higher perceived stigma has been found towards support groups in those who choose not to attend, as opposed to those who do (Goldstein, 2005; Levy & Derby, 1992). In addition, feelings of being devalued and unattractive are typical domains of shame, and can lead to less affiliation with others (Gilbert, 1997). This also suggests that the utilisation of support groups will be less likely for those who suffer shame.

Yet, support groups remain popular with stigmatised populations, (who are more likely to suffer shame; Corrigan, 1998; Ritscher, Otilingham & Grajales, 2003; Link et al, 2001; Byrne, 1997) and those suffering more ‘embarrassing’ illnesses (e.g. Davidson et al, 2000). Lee, Kochman & Sikkema (2002) hypothesised that this contradiction may be explained by the concept that those who suffer higher stigma, are more likely to have been alienated from their usual supports. Therefore, the resulting social isolation may serve to override fear of stigma or exposure in support groups, by inducing them to attend.

One study suggests that it is those who experience higher shame that benefit most from the ameliorating effects of support groups (Hansen et al, 2007). Additionally, those who attend more willingly may find support groups more de-stigmatising (Kingree, 2000). There is probably more difficulty for those who experience most shame and internalised stigma, in accessing the support groups that they need in order to help overcome these feelings.

Thus, support groups are apparently beneficial in ameliorating the effects of shame and internalised stigma (Anh Nguyen et al, 2009; Kingree, 2002; MacInnes & Lewis, 2008; Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007; Dyer-Layer et al, 2004). This has been accomplished through shared spirituality, self-forgiveness, and providing a forum in which to safely disclose shameful experiences. Furthermore, groups have been shown to enable the development of consensus between participants regarding beliefs and responses to internalised stigma, including the opportunity to challenge its perceived legitimacy.

The psycho-educative properties of group support, building self-esteem, and in engaging those who most actively stigmatise attendees have also been demonstrated as beneficial in lessening the effects of shame and internalised stigma. However, support group utilisation may be difficult for this population (Goldstein, 2005; Levy & Derby, 1992; Lee, Kochman & Sikkema, 2002). It is not always understood how shame and internalised stigma has changed in participants of support groups.

This particular area of research in support groups is often also subject to certain limitations, including being reliant on volunteers (usually attendees of specific support groups) rather than random sampling, and being unable to document longitudinal experiences of shame pre-group attendance. Another major sampling bias is a result of the socially inhibiting nature of shame and internalised stigma (e.g. Link et al, 2001; Link 2002; Byrne, 2001): only those who are able to express to others their experiences of shame are available to participate in research.

Those who are too ashamed to participate may be more likely to take part in internet support groups, than face to face support groups (Walther & Boyd 2002), or to leave face to face groups (Pietela, 2002). One of the 8 categories of shame cognitions proposed by Donald Nathanson's theoretical framework is 'seeing and being seen' (Nathanson, 1992), which is physically by-passed in internet support groups. It may also be easier to disclose information (Braithwaite, Waldron & Finn, 1999) due to anonymity (Wright 2000a). Less social status cues also enable more heterogeneity of social relationships and therefore provide less opportunity for comparison (King & Moreggi, 1998).

However, avoidance of feared situations can serve to maintain anxieties, whereas gradual exposure can decrease them (according to Cognitive Behavioural theorists, e.g. Carr & McNulty, 2006). It is possible that the social exposure provided by support group participation is partly responsible for some of the reductions in shame and internalised stigma experienced by participants, and anxious avoidance may explain why many who would most benefit from this exposure, do not access it.

Other limitations in this field of research include the demand characteristics commonly suspected in using self-report measures, which are often distributed by group facilitators, whom participants may fear offending or want to please. It is also limited by the lack of studies in support groups run by consumers, which are peer-led, or which have a control group. As a result, most of the included studies in this review have been run by professionals, and are uncontrolled.

Much of the literature generated by the review has been qualitative in its methodology. Qualitative research, while often supplying a unique insight into the experiences or views of individuals, is subject to the limitations of potential bias, and lack of generalisability (e.g. National Institute for Health and Clinical Excellence, 2007). Conclusions drawn from qualitative studies must therefore be done with these limitations in mind.

Due to the subjective nature of most of the literature in this area, different terms are often used to describe similar concepts. Consequently it has been difficult to establish the validity of grouping such subject matter together. However, it has provided an opportunity to understand how literature on support groups is sub-divided into categories according to terms chosen by authors. Associated terms for ‘support group’ as well as ‘internalised stigma’ were identified iteratively throughout the data collection process, and it was expanded accordingly.

As highlighted by L. Farriz-Kurtz (1997) any definition of a support group describes an ideal type which is seldom reflected in reality. It has therefore been in the interests of this study to measure the many varied groups featured in collated studies against the widely endorsed fundamentals of the support group described by A. Katz and E. Bender (1976; Van Ommeren, M; Saxena, S, & Saraceno, B., 2005, Adamsen & Rasmussen, 2003). Thus, some synthesis of terminology may be provided for those attempting to understand the field of group support and shame.

It is also hoped that the findings may equip clinicians to help potential and actual participants of groups understand how they may be influenced by joining a support group. This may aid motivation to attend, or transcend other barriers to utilisation. It could potentially be accomplished through the simultaneous provision of information about the benefits of support groups with the advertisement of them.

Clinicians may also be informed of the potential utility of focussing on shame in groups, structuring interventions around shame and targeting shame-prone populations with group support interventions. Information regarding support group utilisation and how this may be being thwarted by shame and stigma may provide clinicians with an impetus to think about how groups are advertised and made available. The findings may also point to the importance of researching the role of social psychological processes in groups.

For those with mental health problems, stigma can play a role at any stage of involvement with mental health services; presentation, diagnosis, treatment and outcome (Byrne, 1997). Since support groups can relieve the effects of shame and internalised stigma, support group involvement should not only be accessible, but encouraged. It could be argued that this may circumvent engagement difficulties, as well as prevent the potentially cyclical nature of withdrawal and avoidance which can exacerbate shame.

In summary, this review has found that support groups can ameliorate the negative impacts of experiences of shame and internalised stigma as reported by participants, though there is a lack of explanatory evidence for these findings. Potential engagement difficulties in groups for those who suffer shame and internalised stigma have been outlined, and clinical suggestions applied for group leaders and services.

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Table 1. Included studies, with key to abbreviations.

Authors	Study aims	Sample	Method	Findings	Comments and methodological concerns
Charles, N., Butera-Prinzi, F. & Perlesz, A. (2007)	To explore multi-family group work with families with a parent with an acquired brain injury.	6 families with children between the ages of 7-13 (barring one mother with a four year old daughter).	Quantitative: Pre, post and 3 month follow up measures (GHQ-28, DAS, FAD, BASC) and evaluation form at follow up. Qualitative: Groups were analysed using thematic analysis.	Parents reported reduced levels of distress at follow-up, but high continuing dysfunction, families reported reduced levels of shame.	5 out of 6 families concurrently attending single family therapy. Very small sample size. Reliability of BASC is questionable. Role of researchers is unclear.
Duane, Y., Carr, A., Cherry, J., McGrath, K., & O'Shea, D. (2002)	To document experiences of parents attending a group for families of adolescent CSA perpetrators.	5 parents aged 46-53; two couples and a single mother.	Qualitative: thematic content analysis.	A model was developed from the data proposing relationships between parental shock, shame, self blame, guilt, anger and sadness among others.	No ethics committee approval reported. Semi structured interview questions ethically dubious

Dyer Layer, S., Roberts, C., Wild, K. & Walters, J. (2004)	To determine if a spiritually based grief group decreases shame and other PTSD symptoms in women experiencing post-abortion grief.	35 non-pregnant women between the ages of 18 and 65. 19 attended 8 week group series and 16 took part in weekend group.	Quantitative: pre-test and post-test measures (ISS, IES-R) Qualitative: 11 open ended questions at evaluation	Quantitative: significant decrease in shame (p <.000) and PTSD symptoms (p<.002) Qualitative: More than 80% said their religious beliefs played a very strong role in experiencing the group	The researcher's roles are unclear, and there was no mention of approval from an ethics committee. The study is subject to cultural specificity (US).
Goldstein, D. (2005).	To examine membership utilisation of peer support groups in Vermont State police (VSP), and its relationship to the existence of stigma	141 employees of the VSP	One time point collection of questionnaires	Respondents who use the VSP peer support programme attribute less stigma to its utilisation than those who do not.	Single measure, of which there is no description or indication of standardisation or validity/reliability. Literary quality is poor No mention of consent or confidentiality, or ethical concerns.
Sikkema, K.	To investigate the	177 HIV positive	Quantitative: Participants	HIV and trauma coping group	Potential ethical problems

Hansen, N., Tarakeshwar, N., Nuefeld, S., Meade, C. & Fox, A. (2007)	efficacy of a group intervention and support group for people living with HIV who have experiences child sexual abuse (CSA).	adults (mean age 42 years) who were sexually abused as children.	completed baseline assessment (IES), and were randomly assigned to a coping group, or a support group. Post-test measure then re-administered.	significantly reduced symptoms of trauma compared to support group or wait-list control group. No differences were found between the support group intervention and wait-list control group	in screening for sexual abuse – what constitutes sexual abuse? No heterosexual men included. There was no mention of ethical approval.
Hansen, N., Kershaw, T., Kochman, A. & Sikkema, K. (2007)	To demonstrate the clinical utility of C&RT, using the above study	As above	Quantitative: baseline (IES, TSI, SCL-90-R, WCQ, CWI, HIV & trauma related shame, shame-HIV, shame-CSA, HIV related stress); assigned to a coping group/support group. Post-test measures administered. Non-spec qualitative.	Shame about sexual abuse and dissociative symptoms predicted outcome for the support group condition. Depressive symptoms and active coping strategies predicted outcome for the coping group condition.	As above
Hlongwana, K. & Mkhize, S.	To explore what it means to live with HIV in the	Between 50-90 black south African	Qualitative: non specified, and ethnography	Support group members rationalise their HIV to enhance coping	Potential bias in interpreting data

(2007).	context of Christianity for those attending a South African support group	adults (90% women) 12 of whom were interviewed		abilities, using Christianity as a reference. This involves continuous construction and reconstruction of identity.	Study limitations not reported
Kingree, J. (2000)	To examine predictors and by-products of participation in an Al-Anon group for ACOAs	43 ACOAs (28 males) between age 23 and 60.	Quantitative: Multiple regression analysis to examine potential predictors and repeated measures MANOVA to examine potential by-products (measures: demographic info, substance use, PSSFF, SBSS, self-esteem measure,	Age and self-esteem at baseline predicted level of participation in the MHG, and level of participation was associated with less relapse and more positive changes in SBSS and self esteem at 6 month follow up.	None
Kissman, C. & Torres, O.	To describe mutual support groups for	30 mothers incarcerated in a	Qualitative:	Themes included improved family interactions, problem solving and	Unspecified methodology: lack of rigour in

(2004)	incarcerated mothers	city jail	Non-specified.	the group as a ‘healing support’.	interpretation of data? Roles of researchers not clearly described, ethical issues not reported. No discussion of limitations
Lee, R., Kochman, A. & Sikkema, K. (2002).	To examine Internalised HIV Stigma (IHS) among bereaved HIV positive men and women	268 HIV positive adults (94 women, 174 men) from 4 different states in the US, who had recently experienced an AIDS related loss.	Quantitative: Baseline assessment (demographics including support group attendance; current health status; GRI, CWI, ISEL, BHS, FAHI, IHS, SIGH-AD).	High IHS is associated with recent HIV diagnosis, familial rejection, fear of spreading infection, and non-attendance to support groups	No control group
Levy & Derby, (1992).	To compare widowed spouses who joined a bereavement support group (BSG), and those	40 spouses who joined and 96 who declined	Quantitative: structured interviews and self-report measures (SSES, ‘Three mile island’ adapted items, ISEL,	Joiners showed higher levels of depression, anger, anxiety and subjective stress. Non-joiners showed mild stigmatisation toward	Resulting perceived stigmatisation is qualitatively inferred,

	who did not.		CES-D, POMS-A, POMS-T, IES) completed at baseline, 6 months, 13 months, and 18 months follow up.	BSGs	unmeasured.
Macinnes, D. & Lewis, M. (2008).	To examine the impact of a 6 week group designed to reduce the impact of self-stigma for people with SEMHP	20 Male Inpatients in a London mental health unit mean age 32, diagnosed with a severe and enduring mental illness,	Repeated measures: Pre and post group programme measures: DDS, RSES, SGABS, GHQ-28.	Significant reduction in internalised stigma was observed at follow-up.	Did not report on which aspects of the group were instrumental.
McCay, E., Beanlands, H., Zipursky, R., Roy, P., Leszcz, M., Landeen, J., Ryan, K.,	To evaluate a group intervention designed to promote healthy self-concepts by reducing self-stigmatisation in a sample of young people	47 participants with a diagnosis of a psychotic illness, between the ages of 18-35.	Phase 1 of longitudinal RCT: Demographic info and Repeated measures (MES, TSCS, RSES, SES, LPSQ, QLS, MHS, PANNS, GAF)	Participants quality of life, engulfment and hope improved post group, though self concept, esteem/esteem/efficacy and internalised stigma did not.	It is unclear as to whether this adequately meets the criteria for support group.

Conrad, G., et al (2007)	with psychotic illnesses.				
Nguyen, T.A., Oosterhoff, O., Ngoc, Y.P., Wright, P. & Hardon, P. (2009)	To explore the experiences of 30 HIV infected women in Vietnam in accessing post-natal care.	30 HIV positive women attending a self-help group.	Repeated measures unspecified qualitative methodology.	Most women experienced felt and enacted stigma, which were both improved by involvement in self-help groups.	Also contains data and discussion relating to experiences of shame
Pietilla, M. (2002).	To explore the ways in which members of a support group for family members of relatives who committed suicide	16 relatives of family members who died by suicide	Qualitative: ethnomethodology	Themes emerged of the rights and responsibilities of others, talking in support groups, (including aspects of shame and embarrassment)	This study has a sociological focus and though it presents psychological data, this is analysed more

	talk about their experiences				sociologically than psychologically.
Staerk Buksti, A., Munkner, R., Gade, I., Roved, B., Tvarno, K., Gotze, H. & Haastrup, S. (2006).	To identify elements of family group programme for relatives of schizophrenia sufferers which were most important to them.	35 Relatives of 26 patients with first episode psychosis	Quantitative: One time point collection of questionnaire	Knowledge gained and sharing thoughts and feelings were the most important aspects of the group to family members.	Qualitative methodology may have been more appropriate in addressing participants 'most appreciated aspects'. No control group

ACOAs Adult Children Of Alcoholics, BASC Behaviour Assessment System for Children, BHS Beck Hopelessness scale, C&RT classification and regression trees analysis, CES-D Centre for Epidemiological Studies Depression Scale, CSA Child Sexual Abuse, CWI Coping With Illness, DAS Dyadic Adjustment Scale, DDS Devaluation-Discrimination Scale, FAD family Assessment Device, FAHI Functional Assessment of HIV Infection, GAF Global Assessment of Functioning Scale, GHQ-28 General Health Questionnaire, GRI Grief Reaction Index, IES-R Impact of Events scale Revised, ISEL Instrumental Support Evaluation List, ISS Internalised Shame Scale, LPSQ Link Perceived Stigma Questionnaire, MES Modeified Englulfment Scale, MHG Mutual Help Group, MHS Miller Hope Scale, PANSS Positive and Negative Symptom Scale, POMS-A Anger-Hostility scale, POMS-T Tension-Anxiety Scale, PSSFF perceived Social Support from Family and Friends, QLS Quality of Life Scale, RSES Rosenberg’s Self Esteem Scale, SBSS Status Based Self-Stigmatisation, SEMHP Serious and Enduring Mental Health Problems, SES Self –Efficacy Scale, SIGH-AD Structured Interview Guide for the Hamilton Depression and Anxiety Scales, SSES Social Support Evaluation Scale, TSCS Tennessee Self-Concept Scale.

Table 2. Excluded studies

Exclusion criteria	Number
Shame is not sufficiently featured	9
Focus is on external aspects of stigma	3
Involves (a) group(s) not containing all 5 fundamental elements of the support group	10
Study not empirically based	7
Not written in English	2

Rationale for exclusion criteria

Shame or internalised stigma, were the focus of the experiences of participants of support groups reviewed. Therefore, any study which did not sufficiently feature either of these phenomena was judged to be unable to contribute to meeting the aims of the review. It was also essential that support groups studied that were included in the review contained core attributes of a support group, in order to exclude the many varying types of groups which are similar. For example; many groups that were purely psycho-educative in their aims, and run by professionals were available to be reviewed. However, their inclusion would have jeopardised meeting the aims of the review. Studies were also required to meet a level of empiricism in order to ensure that any conclusions drawn from them would merit some scientific confidence in these. Finally, studies were excluded if not written in English, since the author was limited to an understanding of this language only.

Part Two

The experiences of parents of illicit drug misusers, who have sought help from family support services

This paper is written in the format ready for submission to Addiction Research and Theory. Please see Appendix B for the guidelines for authors.

Word count (excluding abstract, table, qualitative data and references): 7, 835

The experiences of parents of illicit drug misusers, who have sought help from family support services.

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Abstract

The purpose of this study was to explore the experiences of parents of illicit drug misusers who had sought help from family support services, with particular reference to their experiences of shame and stigma. This was operated using a qualitative design in which interviews with 8 parents were transcribed, analysed and presented according to subordinate and super-ordinate themes derived. Main themes included experiences of stigma from treatment agencies, health professionals and the general public, fear of disclosure, tensions and dilemmas revolving around questions of blame and shame, and positive outcomes of group attendance, including a reduction in felt stigma and shame. Suggestions are made regarding the value of support groups for parents of illicit drug misusers and interactions of shame, stigma and group attendance. Relevant clinical implications and future research directions are discussed, as well as limitations of the present study. Key words: parents, misusers, support group, shame, and stigma.

Approximately 330, 000 people develop serious drug problems in the UK every year (National Treatment Agency; NTA, 2008). This has been found to cause considerable psychological harm to close family members of misusers (e.g. DiClemente, 2006; Orford et al, 1998; Orford et al, 2005a) of which there are at least 8 million in the UK alone (Velleman & Templeton, 2003), and on whom the burden of management usually falls (Usher, Jackson & O’Brien 2005). They are also found to be a highly stigmatised population (e.g. Corrigan, Watson & Miller, 2006; Room, 2005; Orford et al, 2005a), which may be due to the association with the misuser, or ‘courtesy stigma’ (Goffman, 1963). In general, drug addiction has been found to be one of the most anger-inducing stigmas, due to the high perceived personal responsibility of those involved (Weiner, 1993).

Until recently, research has largely placed the locus of pathology within the family (Vetere, 1998; Stanton & Todd, 82; Rychtarik et al, 1988; Higgins et al, 1994; Pearson, 2000). For example, the concept of ‘co-dependency’ has been popular in the US since the 1980s with those attempting to describe and understand family members who ‘put up with’ their substance misusing relative (e.g. Cutland, 1998).

However, a small, developing body of research has more recently examined family members with attention to their subjective experiences of stigma (Rey, Rios & Sainz, 1999; Corrigan, Watson & Miller, 2006, Raine, 1994; Room, 2005), stages of adjustment, (Wiseman, 1991) and living with a substance misusing child (Usher, Jackson & O’Brien, 2005; 2007, Jackson & Mannix, 2003), relative or spouse (Orford et al, 2005a; Orford et al, 2005b; Orford et al, 2001; Orford et al, 1992; Orford et al, 1998a; Orford et al, 1998b; Orford et al, 1998c; Velleman et al, 1993).

Among these experiences, shame may contribute to distress (Room, 2005; Corrigan, Watson & Miller, 2006; Orford et al, 2005a; Usher, Jackson & O'Brien, 2007). Shame is a negative self-conscious emotion that has been associated with social isolation, depression, anxiety and the detriment of mental health in general (Elison, 2006; Kulick, 1998; Lewis, 1971; Aslund et al, 2007; Lindsay-Hartz, de Rivera, & Mascolo, 1995; Warmack, 2000; Gilbert & Proctor, 2006).

Shame is often experienced as a result of stigma (Lewis, 1998; Cook, 1983; Turner, Dofny & Dutka, 1994; Wehmeyer, 1994), and in particular, 'perceived'/'felt' stigma (Ritscher, Otilingham & Grajales, 2003, Corrigan, 2004), and 'internalised stigma'/'self stigma' (Ritscher, Otilingham & Grajales, 2003; Link et al 2002; Elison, 2006; Kulick, 1998, Link et al, 2004, Luoma et al, 2007; Scheff, 1998; Byrne, 1997; 2001).

Research into the impact of stigma has lately been dominated by interest in mental illness (Connor & Rosen, 2008). Stigma has been broadly defined as 'a mark or sign of disgrace or discredit, regarded as impressed on or carried by a person or thing' (Brown, 1993). 'Perceived' or felt stigma is stigma which is perceived by the individual to be enacted towards them from an external agent (Luoma et al, 2007).

Internalised stigma is often termed self stigma (Corrigan, 1998; Ritscher, Otilingham, & Grajales, 2003; Link & Phelan, 2001), and both are found to involve the decrement of self esteem through stereotype agreement, and self concurrence with stigma in mental illness (Corrigan, 1998; Van Brakel, 2006; Corrigan, Watson & Barr, 2006).

Family members have been found to suffer from forms of internalised stigma (Corrigan, Watson & Miller, 2006; Orford et al, 2005a), in particular, parents and spouses (Corrigan, Watson & Miller, 2006; Usher, Jackson & O'Brien, 2007). Parental shame in substance misuse can be intensified by, and closely linked to self-blame (Usher, Jackson & O'Brien, 2007). Parents with stigmatised children suffer the same disgrace as their child (Lewis, 1998), and are often believed to be responsible for their children's substance misuse, or described as incompetent (Struening et al, 2001).

Robin Room (2005) found that toward substance misusers, stigma can be used as a form of social control, with positive or negative outcomes. However, this may have associated negative effects on the family. There is some evidence to suggest that family members of illicit drug misusers suffer more perceived stigma than those of alcohol misusers (Room, 2005; Families, drugs and alcohol, 2005; Salter & Clark, 2007).

Both stigma and shame are associated with coping mechanisms involving secrecy, social withdrawal and feelings of low-self esteem and depression (e.g. Link, Struening & Neese-Tod, 2001; Link et al 2002; Byrne, 2001). This is consistent with findings that the experience of shame and social judgement can prevent the utilisation of social support (Corrigan & Watson, 2006; Orford et al, 2005a; Kulick, 1998; Rey, Rios & Sainz, 1999), which is significant because social support is important for coping and recovery in general (e.g. Vollrath, Alnaes & Torgerson 2003), and has been described by family members of substance misusers as such (Orford et al, 2005a).

Social support can also be efficacious in rehabilitation from the negative impacts of shame, in both group or non group contexts (Altrows, 2006; Qianming et al, 2003; O'Brien, 2002; Leichsenring, Beutel & Leibing, 2007; Anh Nguyen et al, 2009; Kingree & Thompson, 2000; MacInnes & Lewis, 2008; Kissman & Torres, 2004; Charles, Butera-Prinzi & Perlesz, 2007; Dyer-Layer et al, 2004; Humphreys et al., 1999; Humphreys & Noke, 1997). However, there is currently limited service provision for supporting family members of substance misusers (Templeton, Zohhadi, & Velleman, 2007; Jackson et al, 2004).

Some specific benefits of support groups are that they have been found to decrease care-giver burden for relatives and spouses of those with mental health problems (Cook, Heller & Picket-Schenk, 1999) and dementia (Gonyea, 1990). Care-giver support groups can reduce embarrassment in dementia care givers, as well as providing a sense of universality (e.g. Wright et al, 1987) and the normalisation of experience (Kahan et al, 1985).

However, despite the above, the author is unaware of any studies examining the impact of support groups on the experience of the parents of substance misusers, who are the relatives most likely to suffer shame and internalised stigma (Streuning et al, 2001; Corrigan, Watson & Miller, 2006; Usher, Jackson & O'Brien, 2007).

In general there has been relatively little research conducted into any negative impact of substance misusing behaviours on family members for the purpose of discovering how the impact can be ameliorated (Orford et al, 2005a; Templeton, Zohhadi, & Velleman, 2007; Corrigan, Watson & Miller, 2006; Usher, Jackson & O'Brien, 2007), particularly in the UK (Orford et al, 2005a). At the same time, increasing recognition is being given clinically to family members; the NTA and the National Institute of Clinical Excellence (NICE) are creating new frameworks within which their needs can be met (NTA, 2006; 2008, NICE; 2007).

Therefore, though it is a topic of national interest, little is known about how shame is experienced in group support, or what the experiences are of parents of illicit drug misusers, who have overcome the barriers of potential stigma and shame to seek help from family support services. It is important to document these (e.g. Orford et al, 2005a; Templeton, Zohhadi, & Velleman, 2007). It is also optimal to understand family members' utilisation of social support, which may impact upon their experience of shame (Orford et al, 2005a; Kulick, 1998; Qianming et al, 2003), including how family members come to be involved with group support services, and how they experience these services.

For the following reasons, a qualitative approach has been chosen for use within this study. Qualitative approaches are concerned with describing the constituent properties of an entity, while quantitative analysis is involved in determining how much of an entity there is (Smith, 2003), therefore a qualitative methodology has been appointed for use in this study. Qualitative methodologies are especially well suited to playing close attention to interpersonal issues, such as shame (Yardley, 2000) and stigma (Link & Phelan, 2001; Shulze & Angermeyer, 2003). Within this approach, parents' experiences are tacit and must speak for themselves (Caelli, 2000).

Despite the tendency of shame to induce hiding and concealment (e.g. Link, Struening & Neese-Tod, 2001; Link et al 2002; Byrne, 2001), participants of research studies have generally been willing to reveal and discuss their experiences of shame (Macdonald, 1998), and studies have shown that people do not necessarily avoid talking about shameful experiences (Rime et al, 1991).

Due to a number of factors described below, this study will focus specifically on the experiences of parents of adult drug misusers. Parents have been found to ‘engage’ more with the substance misuse of their relative, than do children or spouses of substance misusers (Orford et al, 2001). The term ‘engage’ relates to being actively involved with trying to help the misuser (Orford et al, 2001; 2005a). Parents of adult misusing children have not yet been specifically interviewed by the few known qualitative researchers in this area (e.g. Orford et al, 1998; 2005a; Velleman & Templeton, 2003; Usher, Jackson & O’Brien, 2007). Additionally, parents of adult misusers constitute the vast majority of those relatives attending family support groups locally.

This study is therefore concerned with the following research questions. Is shame qualitatively experienced by parents of adult drug misusers as opposed to alcohol misusers or substance misusers in general, and if so, how is this experienced? What are parents’ experiences of stigma and support gained through local drugs services? The aim of the study was to investigate these questions using a qualitative framework to describe and analyse the subjective experiences of parents of illicit drug misusers attending a support group for family members of substance misusers.

METHOD

Participants.

Participants were a convenience sample of parents of illicit substance misusers, recruited from a support group for carers of substance misusers within a voluntary sector organisation for drug problems in the North East of England. This support group was the only one of its kind in the county, and had been identified through the local knowledge of the author. The sample consisted of six mothers and two fathers, whose children were all over the age of 18. Parents completed a Beck Anxiety Inventory (BAI; Beck & Steer, 1990) and Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996) in order to provide a recent indication of parents' mood state on interview. This was in order that consideration of data might be enhanced with a clinical understanding of parents' general emotional functioning, and how this may interact with experiences of their child's misuse. Interviews with these eight participants was considered to provide adequate data to stop recruiting at that number, as data saturation was considered to have been reached; the same themes were repeatedly emerging and there were no new substantial themes. This occurred after around 80% of potential participants had been interviewed.

The number recruited is also consistent with recommendations from the creator of the chosen qualitative mode of investigation; Interpretation Phenomenological Analysis (IPA) for this type of research (Smith & Osborne, 2003). A description of the sample, including demographic data can be found in Table 1, at the end of the study.

Design

As mentioned above, the study employed a qualitative design, and data were collected using semi-structured interviews. Data collection as well as the analyses, were guided by IPA. This approach was chosen because it aims to gain 'an insider's view' of personal experience (Smith, 2003; Willig, 2001; Murray & Chamberlain, 1999). These experiences, as they are described by participants, are analysed as the individual's meaning-making, or interpretation of their own experiences. IPA also acknowledges and appreciates the value of the researcher's own inevitable biases in interpreting the participants' language. This methodology was judged appropriate for a study in which the subjective nature of interpretation of experiences of shame and stigma, might be analysed. A pilot interview was initially conducted, which was later incorporated into data analysed.

Interview schedule

The interview schedule was designed to collect data relating to experiences of stigma, shame and group support, and can be found in Appendix C. Initial familiarisation questions were asked in order to introduce topics, and to clarify any differences in understanding regarding terms used. For example; prior to asking questions about experiences of shame, the author enquired after parents' understanding of the meaning of this word. Further questions were focussed around the following structure:

- Do you feel you have ever been the victim of stigma because of your relative's substance misuse?
- How would you describe this experience of stigma as a consequence of your relative's substance misuse?

- Have you ever suffered shame as a consequence of your relative's substance misuse?
- How would you describe this experience of shame as a consequence of your relative's substance misuse?
- Tell me about your experiences of attending the support group
- Do you feel that attending the support group has affected your levels of shame regarding your relative's misuse?

The interview style was flexible and interviewees were often asked further questions to achieve deeper understanding, as is permissible within an IPA framework (Smith, 2003).

Procedure

Prior to recruitment, ethical approval was obtained from a local NHS research ethics committee; recommendations from whom, were duly incorporated into the procedure (please see Appendices D and E). Participants were informed about the study via the support group leader, who distributed information sheets provided by the researcher (please see Appendix F). The group leader then liaised with the researcher in order to arrange interviews with the eight parents who consented to take part. Participants signed a consent form prior to the interview (please see Appendix G). This incorporated confirmation of having read and understood the information sheet, understanding that participation was voluntary, consent for interviews to be digitally audio recorded and transcribed, and for their completed BAI and BDI to be used in the study. These mood measures were utilised with consideration of the potential advantages and disadvantages of doing so. Though they may have provided contextual information regarding participant's emotional state through which to view raw data, this was to be used with caution due to the possibility of it biasing the author's interpretations and compromising their validity. Parents then answered some demographics questions (please see Appendix H). Interviews lasted around an hour in each case.

Analysis

Interviews were audio recorded using a digital voice recorder, and transcribed verbatim. Transcripts included notations explaining periods of silences, non-verbal behaviour or communication. They were then read several times for familiarity with the data. ATLAS.ti computer software was used in order to provide an efficient mode in which to make preliminary notations against transcripts, and subsequently develop codes (Muhr, 2004), but it did not directly perform analyses.

These initial codes were succinct summaries of meaningful notations, often amalgamating more than one notation. Participant’s mood measures were consulted in conjunction with the reading of transcripts. Notations were referenced across transcripts, until a final list of codes was produced from the analysis of each transcript. Please see Appendix I for a sample of the analysis procedure. Most of these codes were repeated in the majority of the transcripts, and within the ATLASti program, themes were transparently evidenced to original quotes, facilitating the efficient process of the validation of themes.

This list of codes was then grouped into themes and super-ordinate themes according to the prevalence of codes across transcripts as well as their semantic value. Thus, if a code had occurred in seven transcripts, and was semantically close to another which had only occurred in three; the latter code would be grouped underneath the former. Many codes were also amalgamated at this stage.

Analysis involved an iterative process of cross-referencing themes and returning to the data for validation, with the researcher's own potential biases consistently in mind. According to guidelines for rigour in qualitative research, validation was sought from participants (Elliot et al, 1999); as to the appropriateness with which their data had been interpreted. A mother responded to a request from the author for her views regarding a sample of her transcript that had been coded and presented to her. This participant commented positively on themes derived and provided further extrapolations. These were used to refine themes across data-sets; some themes were consequently expanded, and others condensed. The language chosen to describe some themes, were also revised at this stage in order to preserve the authenticity of the data. The value of this alteration became apparent to the author in discussion with this participant.

With this participants' permission, expert validation was additionally sought from the clinician who ran the group, using the sample of her transcript. Please see Appendix J for further explanation of participant and expert validation procedures. Anonymised extracts of separate transcripts were also analysed by members of an IPA discussion group, in order to provide further consultation regarding the application of data to themes. Thus, some form of triangulation of validation was achieved.

RESULTS

Results of the analysis revealed 6 super-ordinate themes, and 19 subordinate themes in the experience of parents of illicit substance misusers attending a support group, as shown in Table 2.

Table 2. Superordinate and subordinate themes.

Superordinate	Subordinate
Impact of child's misuse	Emotional strain Familial conflict
Experiences of stigma as a parent of a misuser	Anger at feeling stigmatised, not listened to, and excluded from their child's treatment by treatment agencies Feeling stigmatised by statutory services, and natural support systems Held responsible for child's actions Negative impact of stigma; 'as parents we are victims, not criminals' Loyalty to child
Disclosure	Fear of disclosure Positive experiences of disclosure
Experiences of shame	Ashamed of self Ashamed of child Impact of shame
Tensions and dilemmas	Tensions in dealing with child's misuse Tensions between those with different views about substance misuse and how to handle it Tension: who is to blame? Tension: Identity strain
Experiences of the group	Benefits of attending Difficult aspects of group attendance Group: de-shaming and universality of experience

Impact of child’s misuse

Emotional strain

Many parents commented upon the range of emotions that are experienced as a parent of a misuser, as well as the powerful intensity and abrasive impact of them:

> I’ve never gone through so many emotions in my life as what you do when you’re living with an addict, it’s you know, apart form the happy one. I haven’t had that for a long, long time, no it’s um, you just feel as though you’re on a rollercoaster all the time. (participant 4)

> emotionally it just, it erodes you totally, absolutely, totally (participant 1)

Physical ill health also featured as a consequence of living with the strain of caring for a substance misusing child, as did having to ‘be strong for’ them, to the detriment of parents’ own well-being.

Familial conflict

Parents frequently reported conflict in the family, often as a result of being lied to by their children, though they may be the only members of the family who retained a relationship with their child.

> he cant stand his brother, to be totally honest, he really does not like his brother, he doesn’t want him in the house, he wont lend him anything, ‘cos he has and he ain’t got it back or it’s been broken so, he’s totally the opposite to me (participant 8)

For many, the rejection of the substance misusing child by other members of the family was the most painful aspect of familial conflict.

Experiences of stigma as a parent of a misuser

The major subordinate theme within these experiences was: Anger at feeling stigmatised, not listened to, and excluded from their child's treatment by treatment agencies.

> [*the treatment centres*] don't seem to think we have any involvement in the person, I mean yes [*my child has*] got to give permission, that you can be involved in treatment, but just as a parent, you should be tret [*treated*] with some respect, and not something that's come in on somebody's shoes (participant 4).

Many parents felt patronised;

> And they emphasise all the time, 'this is their decision', and 'yes, we appreciate that, but it is our home as well' (participant 4)
>
> It's as if they're: 'We're the drug treatment service, don't interfere' (participant 5)

and unrecognised as an important part of their child's treatment and life:

> it's as if they assume that the addict is an individual without any support network, other than the treatment centre (participant 1).

The anger felt also led to graphic descriptions of the treatment process, in which parents often felt stigma vicariously:

> there's um a lock on the door, and someone has to press the buzzer and you go in there, and it's just like going into prison or something [ ] they don't even go behind a screen or anything, they just come out and slap this thing on the table (participant 1)

Parents also expressed a sense of abandonment by treatment agencies:

> ‘if you ring this number, there will be somebody there you can talk to.’ That is all you want. And like, my other friend whose son’s got killed, like she said she didn’t have nobody, not a soul, and you have, literally, you’re fighting a losing battle. So they did, the treatment services are awful, absolutely awful. (participant 4).

Feeling stigmatised by statutory services, and natural support systems.

Parents reported feeling stigmatised by healthcare workers, the police, and often their own informal support networks. The following example related to a parent for whom actions on behalf of the police were perceived as stigmatizing;

> [*the police think*] ‘it’s your fault they’re like that.’ Ha. So you got no help from them. You say ‘was you stigmatised by your neighbours?’ yes you was. But you were also stigmatised by the police. [ ] we knew what they thought of us because they thought ‘you’re just some druggy’s parents. You brought it on yourself’ (participant 2).

Held responsible for child’s actions.

This was another source of stigma, from neighbours and the general public.

> I think the general public because, they just don’t understand that they’re just normal people. Yeah, they are drug addicts but they’re not the scum of the earth. And unfortunately you’re just categorised (participant 2)

Parents also experienced stigmatisation by association with their child when in public;

> I’ve noticed it, you sit on the bus with him, and people know that he’s a druggie, [ ] and they sort of look at you, or you’ll say something sort of in connection with him and you’ll have people like this [*looking round at her*] or they’ll move away from you. If you’re walking with him, people will move away from you, or they’ll stop on the street, so that they don’t have to be near you. (participant 8).

> [*on receiving a visit from son in hospital whilst he is high*] I’ve never felt so embarrassed in all my life, I said ‘I talk about my son, and I’m proud of him, and then you come and do that to me’, so there’s, there’s all that side, there is a massive, massive stigma, (participant 4)

Most parents described anticipating stigma in public situations;

> he’s like the grim reaper, [ ] I walk to work because it’s only 10 minutes away, and I see him coming over the hill, and I think to myself ‘god, I hope nobody sees me coming home from work’[ ]‘what are they going to think?’ (participant 5).

Negative impact of stigma; ‘as parents we are victims, not criminals’.

This was an important subordinate theme, extracted from many instances of perceived injustice due to powerlessness experienced by parents.

> [*on the disclosure of son’s confidential information by a doctor*] I mean at the end of the day, somebody wouldn’t come round a bed, if a patient was terminally ill with cancer, and there were other people there, they wouldn’t discuss things like that in front of them, it just wouldn’t be done. (participant 1)

Injustices included instances of violence by local people:

> I've had my window's nearly smashed in, because of him [ ] I've had people come after him, come into my house and, not bothering whether me or my other son was there or not (participant 8)

Parents' experiences of stigmatisation sometimes led to empathy with other stigmatised groups:

> people that are from prison, [ ] they just assume 'oh no, not on our doorstep, oh they're violent and nasty people,' believe me a lot of people in prison aren't nasty at all, a lot of people in prison, their lives have literally fallen apart (participant 6)

One mother described how she felt that stigmatisation had threatened the bond between herself and her son:

> you always try and have that bond, and try and keep that bond, and when people say that about you, it sort of breaks that up a bit, do you know what I mean? 'cos it makes it harder to keep that bond, 'cos you get affected by what people say (participant 8).

Loyalty to child

Most parents expressed loyalty toward their children in the face of both felt and enacted stigma experienced by both themselves and their children.

> to me he's still my child, no matter what age he gets to he's still my son,
> my first born son, and you have that, you always have that bond (participant 8).
> when he comes to Asda and they look at him and, you know what's going through their mind, and there's still that part of you wants to say, 'hang on a

> minute, he’s still my son, and I love him, and he’s not bad, and he’s a good joiner, and [ ] you don’t know him’ (participant 5)

Some parents expressed this loyalty by conceptualizing their child’s misuse as a biological problem, over which they have little control:

> it’s an illness [*son’s substance misuse*] just the same as cancer, [ ] it’s an illness (participant 5)

> I don’t know as well if it’s something in the genes, handed down, I think there’s a good argument for that actually, because my ex’s mother, she was an alcoholic as well, whereas [*son’s father*] my ex: it was drink. With [*son*] it’s drugs (participant 6)

> someone once said to me, it was a mother actually, of an addict, and she said to me, believe me, heroine is bigger than any of us, and do you know, I can remember those words and I thought ‘God, she is so, so right’ (participant 3).

Much of the data provided by participants within this theme was dominated by a focus on their child’s experiences of stigma, including how this was vicariously experienced by themselves.

Disclosure.

Fear of disclosure

This subordinate theme contained several facets: including not wanting to become a burden;

> even though my family[ ], and [ ] my friends know, [ ] it’s gone on that long that you know you feel like you’re a broken record and nobody wants to know, so

> then you start holding back, you don't tell people. You don't tell people anything really. (participant 7)

the fear of blame;

> I think, you're afraid of blame, that's the best way I can describe it, and it's so embarrassing and you don't tell people, and if people start talking about it, you sort of play a wide berth, and don't say anything, because you are so embarrassed about it. (participant 2)

Shame:

> well, I wouldn't go around telling anybody that my son was a drug addict because I feel so embarrassed about it, so that's my definition of shame: 'embarrassment' really (participant 7)

and most parents reported fear of stigma as having prevented them from disclosing their child's misuse, and for some this was believed to be the reason why stigma had not been experienced;

> unless I've been actually forced to tell…. I started a new job actually in October, so I've only been where I've worked four months, and nobody does know, mainly because, erm, because of the stigma that does go with it (participant 7).

Positive experiences of disclosure

Due to emotional breakdowns at work, two parents disclosed their son's misuse to colleagues:

> I broke down, and [ ] she said, ‘I don’t know what you’re crying for [ ] because my brother, my brother is’ - so there are people out there that, d’you know, have the same things going on in their lives that you don’t know about either (participant 5).

> ‘between you and me’ she said, ‘there are people in this company as well that have got sons and daughters in a similar predicament’ so I do feel, it didn’t make me feel isolated (participant 1)

Experiences of shame

Ashamed of self

Being ashamed of oneself as a parent and being ashamed of one’s child could not be entirely categorized as separate themes, however parents described feeling ashamed of themselves due to ‘giving in’ to their child’s requests for money and other help, and thus feeling as though they were responsible;

> I’m so ashamed of myself, because I should have been stronger, but it’s not as easy as that (participant 8)

Others felt shame due to a general sense of failure as a parent;

> I feel shame all the time, because like, I know a lot of people in my area know that I’ve got a son who’s on drugs, [ ] and part of me will always think that I’ve failed him (participant 5).

> You feel guilty and ashamed of it, and a bit of a failure because you’ve failed as a parent [ ] I would describe [*shame*] as a feeling of being responsible for something that isn’t socially acceptable (participant 7).

> I feel [ ] guilty ‘cos [ ] I know it’s not my fault but sometimes you think ‘that’s my son that’s doing that, I should have some sort of control over him’, although I don’t, I know that I don’t, but you still think ‘Oh my God,’ you still feel like - ashamed in a way, [ ] that you cant do anything (participant 8)

which may be a consequence of perceived public stigma toward the self:

> yeah, at the end of the day in all reality he was a drug addict, yeah, so you know, maybe you get that ‘lower’ feeling as well, you know that’s what comes across [ ] that maybe, yeah, it is partly your fault, you know (participant 7)

Another area of shame of the self which presented itself for many parents was due to what may be called an ‘identity clash’, in which parents were ashamed of who they had become, as a result of their child’s misuse:

> You don’t want to be one of the statistics, you don’t want to be ….. ‘smack-head’s mum’ sort of thing, you don’t - you are but [ ] it’s not what you want (participant 8).

Ashamed of child

The following data are examples of shame of the substance misusing child, which in some instances was perceived to bring shame upon the parent;

> I don’t know anybody who would, who wouldn’t be ashamed of their child [ ] part of me will always feel ashamed of him as well sometimes because I feel like he’s letting me down (participant 8)

Shame also occurred for parents whose children displayed drug-induced symptoms of psychosis in public places;

> he was going outside and shouting ‘I can hear you talking’ but there was nobody there, [ ] and both neighbours knew what was going on, it was like ‘oh, can I just go in and like, crawl under the floor, I just felt like going in [ ] and crawling, sometimes you just feel like you [ ] want to be invisible (participant 8).

Parents also commonly felt shame as a result of their child’s physical appearance in public places;

> it must have been whatever he took, and he had a long t shirt on, his hair was up like Ken Dodd, stuck up in the air, he had a pair of shorts on, and he had a pair of slippers on with like little faces on the top. And I looked at him, I went, ‘oh no’, he came walking up ‘oh hiya Dad’, I went ‘oh’….(participant 2)

> Like in some respects I have actually felt ashamed, I have actually felt shame. Like, when, say I’ve been shopping round Asda, and [*son*]’s turned up (participant 5).

Shame was explained as being experienced vicariously, as a result of being so closely related;

> I suppose any other kind of shame is through what you’ve done, really, it’s through your own actions (participant 7)

> you think they might think it’s me, and so there is a bit of shame in that kind of thing (participant 1).

Impact of shame.

Feeling shame in itself appeared to present a further burden to parents, including guilt:

> [*when asked if the shame she felt about her son's misuse was different to other types of shame*] yeah I suppose it is because I've never, um, because he is my son, and you know, you never want to feel ashamed of your children, you know, because you love them too much (participant 4)
>
> you don't want to feel [*shame*], erm, it's a natural instinct for a parent to feel proud of a child (participant 7).

And social isolation;

> I don't see them [*friends*] as much as I used to, you know, because of 'what's the situation going to be like at home?' you know, you don't know if he's going to turn up or not (participant 1).
>
> I can't mix with people, I feel people know me as his mother, I feel I can't hold my head up high (participant 6).

Social isolation was in turn felt by some parents to foster further shame. Shame was also reported by one father to make him 'short – tempered', and was felt to be something that should be dealt with by keeping it sub-conscious.

Tensions and dilemmas

Tensions in dealing with child's misuse

Some parents were evidently torn between the desire to seek more help in dealing with their child's misuse, and finding the strength to deal with it independently;

> I think you know, he [*partner*] should be here to help me with this. But at the end of the day I know really I've got to find the strength to do this, for me. (participant 5)

> It's my dearest wish to find the strength within myself to deal with this (participant 1)

All parents endorsed the necessity of laying down boundaries between themselves and their children, though this often contradicted their instincts;

> I want to get out of that as well [*not inviting friends to her house*], I want to stop doing that, you know, and if [*son*] comes say, 'I've got people coming, you'll have to go', I want to find that strength to maybe do that (participant 5)

> Once they reach the age of 18, they're responsible for their own actions. I've done my bit, maybe, alright, you're continuously looking after your children for the rest of their life, but there comes a point where they are responsible for their own actions, and that's where you have to draw the line (participant 2)

Tensions between those with different views about substance misuse and how to handle it

Most parents described experiencing this tension, either in the support group or among natural social supports

> I think of something I'll tell them [*group*] straight away, I've got to say what I've got to say and they don't like it (participant 2)

> that was another thing the other night, something about hope was mentioned, and [*partner*] said 'oh, that don't get you very far.' Now, that got me really

> angry, and I said ‘at the end of the day [*partner*], that’s all I’ve got, that’s all I’ve got at the moment’ (participant 5)

This tension was described as a reason as to why their child’s misuse was not discussed among group, family and friends for some parents

> I think that’s why I used to keep a lot from her, because, she does have different ways of dealing with it (participant 5)

> I think sometimes you have to just tell people as much as you need them to know, and that was definitely that sort of a situation, if I’d have said something, I reckon, I might not have been here now (participant 8).

Tension: who is to blame?

Most parents reported finding themselves searching for answers as to why their child’s misuse had come about, and this involved hypothesizing where the blame lay. Most parents oscillated between blaming themselves and their child;

> I feel like I’ve let him down, but then I feel like he’s letting me down as well (participant 8)

> I feel as if I’ve failed, terribly. Because I did treat him, he is my own son. [ ] he always had somebody at home to welcome him from school, but I do feel that I could have done more for him, could have loved him more (participant 6)

> and I’m ashamed that I’ve, I worry I might have done something that might have affected him (participant 1)

> People always say if they really want to do it, they'll do it, [*withdraw from substances*] but I don't know (participant 4)

Some parents partly blamed environmental or other factors:

> I'll be the last person to make excuses because I'm very anti, but um, different circumstances cause it don't they, at the end of the day (participant 4).

> they keep saying everywhere you go that it's got to be up to him, he's got to do it, I don't think it's all up to him (participant 6)

These tensions meant that parents were not always sure whether stigma experienced toward themselves or toward their child was actually justified; a further tension;

> at the time you let that go [*stigma*], because you think, well he is a drug user, you know and it isn't until later you think he had no right to do that (participant 5)

> you're sort of drawn away from the normal, uh, area, [*in treatment services*] which I don't know whether that's a good thing or a bad thing (participant 1)

Searching for answers to questions about who, or what is to blame, was experienced by many parents as a demanding vicious cycle;

> all you're asking yourself all the time is 'why?', you really, are you know, because I had gone round absolutely every corner, asking every question I could possibly ask, directly, and indirectly, and I've got nowhere. (participant 7)

> I don't know, was he predisposed to it? Did we not help, blah de blah de blah, there isn't an answer (participant 1).

Tension: identity strain

Parents often described finding themselves ‘living in two worlds’ due to the difficulty disclosing their child’s substance misuse to colleagues and acquaintances, and sometimes, family. This in turn created a tension in identity, existing as a person to those who know them as a parent of a drug misuser, and to those who do not.

> you know, you hear ‘druggies’. And as soon as I hear that I go cold (participant 5)

> I’m aware, that, that there are people who like to ‘chattle’ about it, you know, and that they have a very strong opinion of ‘druggies’ you know in inverted commas (participant 1).

Identity strain was a tension also experienced as a result of shame and the disparity between how the parent sees themselves, and how they see their child

> you know I was always taught that you respect your elders you know, and the thought of him sort of sitting there, in handcuffs you know, in, in and I ‘m thinking oh you know it’s just appalling and I do feel sort of ashamed of him, that’s awful, [ ] but it’s such an alien world isn’t it to inhabit. (participant 1).

Experiences of the group

Benefits of attending

Many parents explained that they had begun attending the group when at the end of their own resources;

> I think that’s actually what brought me to [*the group*] because I couldn’t deal with the feelings anymore, I’d just got to the stage where, you know, where you

> just really don't know which way to turn. I felt ill, you know... isolated…. really, really alone (participant 5)

Some parents also described feeling rescued by the group;

> coming here has been my salvation [ ] oh, just let me get to Wednesday [*group meeting day*] [ ] and it's, it's a proper little lifesaver (participant 1)

> when I first came, I found the group to be a lifeline, - is the only way of describing it (participant 8)

and gratefulness at having somewhere to go where they would not be judged;

> it's so important to have somewhere to come that you're not actually being judged. You're with a group of people who are experiencing the same thing, and they're not going to be saying 'oh you know, you shouldn't be doing this, you shouldn't be doing that (participant 1)

Some parents directly contrasted their experiences of the group, with their experiences of treatment agencies;

> This is how it should be, if there's a model of how things should be, this is much more like you would hope to see rather than the other side (participant 1)

For many parents, the group was experienced as a safe haven in which they could offload:

> it was my only safe haven….and still is, it's the only place where I can talk to people who are going through exactly the same things, where I can not just relate

> to them, but we can support each other as well, we can help each other we can lift each other up (participant 8)

> I mean these support groups are really good because, say you've had a real bad week, [ ] you can come, and you can offload, and rather than keeping it in, offloading helps, such a lot, it really does, so yeah, they've been absolutely wonderful for me. (participant 5)

Many also found the group to provide them with relief;

> [*group*] gives you a focus other than the destructive chaos going on around you (participant 1).

And empowerment, as well as role models and mentors who provided hope;

> you think how, how they can do it, so you can do it, because they've had to deal with it for much longer than you have. And they're still dealing with it, and they're still here and they're, you know they're nice people (participant 1)

Some parents appreciated the encouragement that the group gave them to have a social life of their own, as well as providing some practical coping strategies through learning from one another's experience;

> how other people deal with their problems. I think that helps a lot as well (participant 7).

Most parents appreciated the warmth and emotional support gained by attendance;

> say you know [*group member to a group member*], ‘I’m not saying it’s gonna get any better but we’re all here, we’ve all been there, we’re all there, and we know what you’re going through’ (participant 8)

> she needs a good pat on the back [*group leader*]. She is a very warm person, for the simple reason that she has experienced it herself (participant 6)

Difficult aspects of group attendance

For some parents, attending the group brought with it a deeper consciousness of their status as the parent of a misuser. One parent described feeling ashamed the first time he attended a group meeting;

> [*group leader*] said would you like to come to the group meetings? we said yeah, we’d give it a try. And - it’s when you, you know the initial part of a meeting when everybody’s just sat there and you - you don’t know anybody there, and you’re actually sort of ashamed, guilty, [ ] that actually, that you have - well, not that you have to be there, but that you’re involved with this group (participant 7)

Another described the fear of stigmatisation from other group members;

> I think maybe meeting them personally, as a group, I feel awkward. Because they recognise you - I might see them in the street somewhere and I [ ] just feel that they’d recognise me, if they see my face they might, even thought they have the same problem themselves, I might feel as if I’m branded, I know it’s stupid to think that , but I just do (participant 2)

A further difficult aspect of group attendance for some is detailed above within the theme ‘Tensions between those with different views about substance misuse and how to handle it’.

Group: de-shaming and universality of experience

> it’s less of a failure as a group, I don’t think you’re ever gonna get rid of that feeling, that feeling is gonna stay there whatever, um, but you are not the only one, other people have experienced that so, ‘yes you’re still a failure’ or ‘yes, erm, or there have been failings’, but other people have made their mistakes as well, it’s perfectly normal to make mistakes, you are not outside a group, you are not unique. I think that’s the best part of it (participant 7)

> I think they’ve made me feel less ashamed, not just of me, but of my son as well, because, you just have the realisation that it’s not just you - you’re not the only one, you’re not out there on your own, you’re not the only person, it felt like you weren’t the only couple like this (participant 4).

Despite this almost unanimous experience among the parents, it is unclear as to whether this de-shaming and de-stigmatising effect carried outside of the group for those who experienced it:

> to the other people [*outside the group*] [ ] it don’t change it to the outside world shall we say, but people who are in the same position as you are, you don’t feel stigmatised at all when you are with them (participant 7)

Helping others was also therapeutic for some;

> yeah it definitely did do that actually [*helped her feel less ashamed*], but I think it, it’s not just them helping me, I think it’s me helping them as well, we all, we all help each other,[ ] I always feel better helping people (participant 8)

and another parent found that she could process her own problems by
listening to others.

DISCUSSION

The parents involved in this study were very eager to participate; as they explained, it provided a sense of getting their voices heard, and being listened to; something previously observed in parents of adolescent misusers by Usher, Jackson & O’Brien (2007). This was implicitly inherent in many of the themes derived. Themes include some new concepts for the field of research into the experiences of parents of misusers, as well as some which provide support for extant literature.

Stigma, shame, and treatment agencies

Perhaps the most striking of these novel themes, were those which indicated that stigma was largely perceived from the very sources of community provision that one might expect to rely on under such circumstances. The uniqueness of this finding may be due to the current study being the first study known to the author to be conducted qualitatively with parents of adult misusers within the UK.

Undercurrents of blame as a source of stigma toward parents of misusers from healthcare workers in Australia have previously been observed in parents’ experiences (Jackson & Mannix, 2003; Usher, Jackson & O’Brien, 2007), and stigma from health and social services has been observed toward those with various health conditions (Van Brakel, 2006). However, the prevalence, ubiquity, and detail of this theme in the current study provide a deeper awareness of how parents of misusers can be affected by stigma.

According to Clive Seale (2002), there are three main ways one can be stigmatised; through blemishes in appearance, blemishes on the character, and tribal stigma; being stigmatised because you belong to a group. It could be argued that all three of these were in some way found to be experienced by parents of misusers in this study.

Blemishes in appearance are demonstrated by the stigma felt by association with the appearance of their substance misusing child in public: “If you’re walking with him...people will move away from you” (participant 8; Theme: stigma, held responsible for child’s actions). Blemishes on the character were described by parents as being given. For example: “they [*police*] thought ‘you’re just some druggy’s parents. You brought it on yourself.” (Participant 2: Theme stigma; feeling stigmatised by statutory services and natural support systems).

Finally, tribal stigma was described in being a parent of a misuser: “as a parent, you should be tret [*treated*] with some respect, and not something that’s come in on somebody’s shoes” (participant4; experiences of stigma as a parent of a misuse; feeling stigmatised, not listened to, and excluded from child’s treatment by treatment agencies).

Parents also demonstrated, or described the desire to demonstrate the spectrum of coping approaches to stigma, outlined by Link et al (2002).

These are secrecy: “I wouldn’t go around telling anybody that my son was a drug addict because I feel so embarrassed about it” (participant 7, theme; fear of disclosure); social withdrawal: “I don’t see them [*friends*] a much as I used to [ ] you don’t know if he’s going to turn up or not” (participant 1, theme; impact of shame); educating stigmatisers and challenging stigmatising behaviour: “there’s still that part of you that wants to say....he’s not bad...and you don’t know him” (participant 5: theme; stigma, loyalty to child) and distancing themselves from their children as a stigmatised group: “I see him coming over the hill and I think to myself ‘God, I hope nobody sees me coming home from work [ ] what are they going to think?’” (participant5; theme, stigma; held responsible for child’s actions).

In general, the presence of stigma toward the drug addicted population and their family members warrants more research into how this may be experienced differently than by those with mental illnesses per se (Connor & Rosen, 2003). Some parents provided evidence of multiple perceived stigma, due to the drug induced psychoses manifested by their children in public. Prior research into the damaging effect of multiple stigmas has focussed on drug addiction and HIV (Connor & Rosen, 2003; Reidpath & Chan, 2005) and in the future may broaden its’ scope with the consideration of the impact of psychosis experienced by this population and their family members.

For the field of mental health, what may be most significant about these experiences of stigma is the perception of them, and further; their internalisation (Link et al, 2004; Scheff, 1998; Byrne, 1997; 2001). Researchers have asserted that subsequent to the perception of stigma toward oneself, internalisation of that stigma can occur, in which negative stereotypes are inwardly applied, resulting in devaluation, shame and withdrawal (Corrigan, 1998; Ritscher, Otilingham, & Grajales, 2003; Link & Phelan, 2001). This is sometimes called ‘self stigma’, and can lead to low self-esteem, low-self efficacy (Link, et al, 2001; Markowitz, 1998) and can be experienced as shame (Corrigan, 2004).

The current study yielded some evidence for internalised stigma. Parents experienced a tension which involved resisting stigma against oneself, yet at the same time rationalising others' stigmatising behaviour as being justified. For example under the theme tensions: Who is to blame: "you're sort of drawn away from the normal, uh, area, [*in treatment services*] which I don't know whether that's a good thing or a bad thing" (participant 1).

A global sense of failure, which is a typical manifestation of shame (Lewis, 1971; Nathanson, 1992; Tangney, 1995), was also experienced by parents as a result of internalised stigma. For this reason, according to the themes derived in this study, parents may not only perceive stigma, but they may be more vulnerable to an inclination to self-stigmatise. This is due to their propensity to blame themselves, feel like failures, continuously question their conduct and adequacy as parents, and feel ashamed of themselves (Link et al 2002; Elison, 2006; Kulick, 1998, Link et al, 2004, Luoma et al, 2007; Scheff, 1998; Byrne, 1997; 2001).

Self blame, a sense of inadequacy and failure, observed in this study, are experiences of parents of misusers found by researchers previously (Corrigan, 2004; Orford et al, 2005a; Usher, Jackson & O'Brien, 2007) and have been included in definitions of shame (Lewis, 1995; Tangney, 1990).

Michael Lewis (1998) theorised that self blame is integral to the relationship between shame and stigma, due to the issue of responsibility: "The degree to which stigmatised persons can blame themselves or are blamed by others for their condition reflects their degree of shame." (p127). This may be evidenced in parents' expressing continual feelings of responsibility, self-blame and shame (see theme: 'Tensions: who is to blame?'). An underlying sense of responsibility may contribute to all experiences described within the 'Tensions and dilemmas' superordinate theme. Responsibility is therefore an important concept when considering parents' experiences generally.

There is evidence to suggest that shame can be altered in parents of stigmatised children by challenging cognitive distortions based on self-blame and responsibility (in a study of parents of children with learning disabilities; Nixon & Singer, 1993). Further research may be required in order to assess the value of such strategies for parents of misusers.

'Social shame' or 're-integrative shaming' has been hypothesised to serve a necessary function for society, by providing a deterrent to socially unacceptable behaviour (Braithwaite, 1989). Social shame has been distinguished from 'malignant shame', which can inhibit social functioning (Hadar, 2008; Houts, 1995; Link et al, 2001; Link 2002; Byrne, 2001).

Within themes of tensions for parents in this study, it is apparent that the relative usefulness of social shame transgresses its boundaries and becomes malignant, when parents find themselves constantly questioning their role and responsibility in the misuse, identity and worth as a parent. Evidence from this study suggests that parent's experiences of stigma, particularly from services, may encourage malignant shame, by excluding them from treatment and adding to a sense of powerlessness. This was described by participant 8; "I should have some sort of control over him [ ] you [ ] feel like, ashamed in a way, [ ] that you can't do anything." (theme; ashamed of self).

Parents’ experiences of aloneness as a result of shame are consistent with previous research, into how shame and stigma can both induce social isolation (Link et al, 2001; Link 2002; Byrne, 2001; Retzinger, 1995). Further, stigmatisation from treatment agencies and the police, as bodies of authority may compound the sense of isolation co-existing in parents as a result of feeling stigmatised by neighbours and the general public. It was apparent that for many parents, this isolation made their burden hard to bear. Feeling excluded from their child’s treatment by treatment agencies was particularly difficult, and may have exacerbated feelings of isolation particularly because drug services do not have the capacity to help parents in their own right (Jackson et al, 2004).

Difficulties for mental health professionals in balancing their clients’ rights to confidentiality, with relatives’ needs for information have been documented (Bogart & Solomon, 1999) and may be applicable to drugs treatment agencies also. The experiences of parents documented within this study, and a previous study into the experiences of parents of misusers (Usher, Jackson & O’Brien, 2007) would suggest that the balance of current practices should be analysed with family member’s needs in mind.

This may involve pragmatic social considerations relevant to parents’ interaction with treatment agencies: parents described much of their experiences of stigmatisation as a result of the lack of human contact, perhaps more than of the presence of it. Parents described how the de-stigmatising and de-shaming impact of the group did not always have associated effects outside of the group (see theme; Group, de-shaming and universality of experience). Therefore support groups facilitators may need help, to bridge the potential gap between these two arenas. Treatment agencies could potentially liaise more with parents in a manner that is engaging of the parent, yet still respectful of the misusing child's confidential information.

Group support & tensions; clinical implications and future research directions.

Parents' experiences of group support are a new contribution to the literature, and as such deserve attention here. To begin with; the cumulative impact of the isolating effects of shame on experiences of group support utilisation was that parents tended to override feelings of shame and fears of stigmatisation to access the group only when they were desperate (Lee, Kochman & Sikkema, 2002).

For example:

> I think that's actually what brought me to [*the group*] because I couldn't deal with the feelings anymore, I'd just got to the stage where, you know, where you just really don't know which way to turn. I felt ill, you know... isolated…. really, really alone (participant 5, theme; Group: benefits of attending)

Internalised stigma can prevent the utilisation of support (Corrigan, 2004), as can perceived stigma for family members of substance misusers (Orford et al 2005a, Qianming et al, 2003). As a result of this, parents of substance misusers may find computer-mediated support groups more attractive (Wright, 2000a; Wright & Bell, 1998), and many may be preferentially utilising them over face to face support groups.

However, the present study describes a sample of parents who consistently experienced the benefits of a face-to-face support group, including its' de-shaming and de-stigmatising properties, which occurred mainly through gaining a sense of universality of experience. It has been theorised that the group is the ultimate arena for the amelioration of shame, due to the presence of the body, which bears automatic physical manifestations of shame (such as blushing); thereby removing the obstacle of secrecy in communication of shame (Hadar, 2008). In this sense, it may be conjectured that the initially difficult accessing of the group may have broken an avoidance pattern (e.g. Clark & Wells, 1995).

Most parents volunteered their views about how the support group starkly contrasted to their experiences of treatment agencies, in relation to stigmatising attitudes perceived versus the openness and non judging approach of the support group.

However, some parents described finding the initial accessing of the group induced a feeling of shame. Feelings of shame have been reported in participants of support groups before as being a result of their attendance (Staerk-Burksti et al, 2006). Additionally, some have argued that support groups can damage self-esteem by reinforcing participants’ identities as members of stigmatised groups (Coates and Winston, 1983; Seale, 2002).

Fear of stigmatisation from other group members was evidenced in this study (see theme ‘Group; difficult aspects of group attendance’). Within the theme ‘tensions between those with different views about substance misuse and how to handle it’, group members described withholding information due to these tensions. This may warrant further research; individual support services within treatment agencies may be beneficial in compensating for this difficulty felt in the group, and if feasible, should be made more available.

The finding that some participants experienced shame on initial joining of the group, may be alternatively conceptualized as comparable with a phenomenon documented by

Bruce Link and colleagues (2001), in which the effect of stigma for those accessing support for mental health problems is greater when treatment is initiated. This initial feeling of shame may also be referenced to the initial anxiety experienced by those with phobias, when exposed to their fear (Clark & Wells, 1995; Rapee & Heimberg, 1997).

Further, the amelioration of shame, internalised stigma, and feelings of isolation which have resulted from group attendance for parents, may be paralleled to the positive outcomes of exposure to feared situations which sufferers of anxiety can experience. This has been found chiefly by cognitive behavioural theorists, who assert that disconfirmation of fears are experienced through breaking the behavioural avoidance cycle and gradually exposing oneself to feared situations (Clark & Wells, 1995; Rapee & Heimberg, 1997).

This maintenance cycle disruption may also be reflected in the positive experiences of some parents, of disclosure, when forced to tell work colleagues or neighbours about their child's misuse. This occurred though most parents said they believed withholding disclosure was the chief reason for not having experienced more stigma, a finding very similar to that of a study of HIV-affected care givers (Cannon-Poindexter & Linsk, 1999).

Clinicians and group leaders may benefit group members by providing assertiveness training for those parents who wish to be more explicit in everyday circumstances about their child's misuse. This may provide the impetus for the breaking of maintenance patterns, within the wider contextual framework of cognitive behavioural theory, the presentation and discussion of which, may be a further possible psycho-educational intervention for parents.

Parents not only benefited therapeutically from one another's input, but confirmed prior findings that support group attendees can benefit from helping others and thereby personally adjust to challenging experiences (Loewenstein et al, 2008 & Burns & Taylor, 1998). Therapeutic benefits, in the absence of a professional intervention are not a novel finding (Davidson & McGlashan, 1997; Davidson et al, 1999; Lin & Kleinman, 1988; Durlak, 1979; Christensen & Jacobson, 1994).

The benefits demonstrated in experiences of parents in the current study suggest that the growing number of support groups (Roberts & Salem, 1999) for stigmatised populations ought to be made as accessible as possible, so that they may be available to those who might never actively seek support without prompts, or who may only seek support when all other resources are exhausted. This may be accomplished through raising the profile of such groups through media within GP surgeries or other community access points, and ideally, through treatment agencies themselves.

The experience of internalised stigma has been associated with both little personal empowerment gained from traditional treatment in mental health, as well as poor treatment adherence (Sirey et al, 2001). Consumer operated self-help services are perhaps the best examples of practices that facilitate empowerment (Davidson et al., 1999, Wilson, Flanagan & Rynders, 1999; Barrera, 1986). This suggests that support groups may be the more viable mode of support for stigmatised populations, as well as the cheaper option, and funding should reflect this accordingly.

A potentially beneficial clinical application for support groups may be the opportunity for the basic training of support group leaders in psycho-education (Anh Nguyen et al, 2008) regarding the value of disclosure. This may be provided through the principles of cognitive behavioural therapy for example, in which basic maintenance cycles involved in the fear of disclosure, social withdrawal, and perhaps feelings of internalised stigma may be conceptualised. This may further normalise the experience of parents through the presentation of a model beyond the boundaries of being a parent of a substance misuser, and may be used flexibly with respect to the autonomy of peer led support groups.

Additionally, support groups may have the potential to act as forums for direct de-stigmatisation between stigmatisers, and the stigmatised (Anh Nguyen et al, 2009; Byrne, 1997). Social contact is one of the three modes of stigma reduction most commonly utilised in the community (Corrigan & Penn, 1999), and has had some effect in generating more positive views in the general public (Corrigan et al, 2002). Support groups provide this contact, on an equal basis, which is a vital consideration if de-stigmatisation is to occur (Corrigan & Penn, 1999). However, if the purpose of de-stigmatisation in the community should develop for the support group, clinicians may face the delicate task of ensuring that groups do not lose their autonomous function, by adopting aims beyond meeting the needs of the individuals in the groups. Future research may be needed to assess this consideration for support groups should they develop this utility.

The experiences documented in this study suggest that these parents may go through stages, according to how long they have been aware of their child’s misuse. Parents who had been aware less than 5 years appeared to experience more ‘tensions’, as well as questioning and grieving (as in previous studies of parents of adolescents; Usher, Jackson & O’Brien, 2007; Jackson & Mannix, 2003), whereas parents who had known of their child’s misuse longer seemed more accepting of the tensions. This may reflect a consistency with Barrie Hopson’s model of transition, in which symptoms of stress can be ameliorated by the acceptance of change which can follow crises (Adams, Hayes & Hopson, 1977), and may be a basis for future quantitative investigation.

Future research into the experiences of parents of substance misusers may be useful in providing clinicians with further awareness of these stages, so that appropriate interventions can be applied to parents at different stages of adjustment. Additionally, parents may find their experiences normalised by the discovery of a pattern of adjustment established by researchers, the prognosis of which may also provide hope for their future.

The findings of the current study imply considerations for the leadership of support groups for parents of misusers. Group leaders may wish to emphasise the legitimacy and likelihood, that parents may employ different strategies for dealing with their child’s misuse at different stages of their awareness of it.

Establishing group ‘norms’ has been found to be an important aspect of group work, because these are linked to reciprocal social exchange, which can influence positive outcomes (Lieberman, 1989). The importance of group norms may be particularly pertinent for the group which the current study is focussed on. This is due to the kind of tensions that have occurred between group members at different stages of adjustment.

An understanding of some of the common tensions experienced by parents of this study may help to further normalise the experiences of those in other groups, particularly if these were to be made more generalisable by further quantitative analysis.

Future research may additionally further the field by examining issues of gender in the experiences of family members of misusers in support groups. Mothers are the relatives most likely to participate actively in self help (Picket, Heller & Cook, 1998), and women in general are probably more likely than men to develop a shame-prone affective style (Lewis, 1976 & Wright, 1987).

Mothers and fathers of misusers in this study may have demonstrated different coping styles; the two fathers involved in this study were the only participants to indicate no depression or anxiety on the self-report measures administrated. That they may have different coping styles is a plausible hypothesis considering evidence for gender differences in these (Arnten, Jansson & Archer, 2008; Hagedoorn et al, 2008) and warrants further quantitative investigation in family members of misusers in order to validate the suggestion derived. Further research in this may be useful by helping to direct practitioners in providing both mothers and fathers with support which accounts for potentially different coping styles.

Limitations

The main limitation of the present study is that due to the inhibiting nature of shame and perceived or internalised stigma, (Link et al, 2001; Link 2002; Byrne, 2001 Tangney, 1993), parents who experience the greatest degree of these may never attend a support group, and may have a different story to tell. However, the interest of this study was in those who had experienced group support, and who would have had to overcome shame and fears of stigmatisation, or any other barriers in order to do so. Nevertheless, the question remains as to how parents who do not utilise group support experience shame and stigma, since those that do claim the benefits of attending, suffer with them.

On reflection, closer attention to participants' previous experiences of depression could have been paid closer attention in the current study, due to the association between shame and depression (Aslund et al, 2007). Future research would further the field by examining whether depressed participants are more likely to internalise stigma as well as suffer shame.

Another limitation, which is a common criticism of qualitative research, concerns the validity and reliability of the data collection and analysis. Evaluating this can be complicated (Yardley, 2000). The benefit of the chosen mode of investigation: Interpretative Phenomenological Analysis (IPA) is that it acknowledges the role that the researcher plays at every stage of data collection, analysis and interpretation (Smith, 2003).

This study has therefore been conducted with the author's potential biases in mind, and the integrity of the data has been consistently monitored, including the involvement of participant and expert validation procedures (see Appendix J), and external validation by colleagues with whom the derivation of themes were discussed.

Conclusions

The current investigation into the experiences of parents of substance misusers attending a support group has yielded some important insights into how parents of misusers may be impacted by the sequelae of their child's misuse. Parents were found to suffer from previously documented burdens such as emotional strain, familial conflict, feeling stigmatised by health professionals and the general public, and suffering shame on behalf of one's child (Usher, Jackson & O'Brien, 2007; Orford et al, 2005a; Struening et al, 2001; Corrigan, Watson & Miller, 2006).

Parents in this study also described suffering the majority of stigma from treatment agencies, whose exclusion of them was experienced in conjunction with stigma and isolation. Parents described public stigma in the context of fear of disclosure and the tension between public and private life, which often occurred in concurrence with shame. Other tensions revolved around a feeling of shame toward the self, identity strain, and questioning who was to blame for their child’s misuse. This involved an overriding tendency to judge themselves as failures. All parents described significant benefits in attending the support group, including the de-shaming and de-stigmatising impact it provided through the sense of universality of meeting other parents in a similar position.

Parents have been widely recognised as an important ally for treatment agencies and governing bodies against the impact of misuse in the community (Orford et al, 2005; NTA, 2006; 2008, NICE; 2007). However, these services may inadvertently reinforce parents’ negative self-focussed cognitions in the realm of stigmatisation and shame, while concurrently adding to a sense of isolation by excluding them from their children’s treatment and being unable to offer support.

Understanding the role that shame and other factors can play in accessing, and continuing to access support is important for developing services appropriate to the needs of parents of substance misusers.

Table 1. Description of the sample.

Age	*M=55, SD=6.3*	Range: 20 years
Employment status		
Employed	6	
Unemployed / student	2	
Depression		
No depression	3	
Mild depression	2	
Moderate depression	3	
Severe depression	0	
Anxiety		
No anxiety	2	
Mild anxiety	1	
Moderate anxiety	3	
Severe anxiety	1	
Child's primary drug		
Heroin	5	
Heroin and another	3	
Length of time child misused	*M=12 SD=6.6*	Range: 20 years
Length of time in group support	*M=7.7 months, SD=4.8*	Range: 12 months

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Part 3: Appendices.

Appendix A: Guidelines for authors for submission to the Journal of Clinical Psychology

Journal of Clinical Psychology

Manuscript Preparation

Format . Number all pages of the manuscript sequentially. Manuscripts should contain each of the following elements in sequence: 1) Title page 2) Abstract 3) Text 4) Acknowledgments 5) References 6) Tables 7) Figures 8) Figure Legends 9) Permissions. Start each element on a new page. Because the ***Journal of Clinical Psychology*** utilizes an anonymous peer-review process, authors' names and affiliations should appear ONLY on the title page of the manuscript. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.

Style . Please follow the stylistic guidelines detailed in the *Publication Manual of the American Psychological Association, Fifth Edition* , available from the American Psychological Association, Washington, D.C. *Webster's New World Dictionary of American English, 3rd College Edition* , is the accepted source for spelling. Define unusual abbreviations at the first mention in the text. The text should be written in a uniform style, and its contents as submitted for consideration should be deemed by the author to be final and suitable for publication.

Reference Style and EndNote . EndNote is a software product that we recommend to our journal authors to help simplify and streamline the research process. Using EndNote's bibliographic management tools, you can search bibliographic databases, build and organize your reference collection, and then instantly output your bibliography in any Wiley journal style. *Download Reference Style for this Journal:* If you already use EndNote, you can download the reference style for this journal. *How to Order:* To learn more about EndNote, or to purchase your own copy, click here . *Technical Support:* If you need assistance using EndNote, contact endnote@isiresearchsoft.com , or visit www.endnote.com/support .

Title Page . The title page should contain the complete title of the manuscript, names and affiliations of all authors, institution(s) at which the work was performed, and name, address (including e-mail address), telephone and telefax numbers of the author responsible for correspondence. Authors should also provide a short title of not more than 45 characters (including spaces), and five to ten key words, that will highlight the subject matter of the article. Please submit the title page as a separate document within the attachment to facilitate the anonymous peer review process.

Abstract . Abstracts are required for research articles, review articles, brief reports, commentaries, and notes from the field. Abstracts must be 120 words or less, and should be intelligible without reference to the text.

Permissions . Reproduction of an unaltered figure, table, or block of text from any non-federal government publication requires permission from the copyright holder. All direct quotations should have a source and page citation. Acknowledgment of source material cannot substitute for written permission. It is the author's responsibility to obtain such written permission from the owner of the rights to this material.

Final Revised Manuscript . A final version of your accepted manuscript should be submitted electronically, using the instructions for electronic submission detailed above.

Artwork Files . Figures should be provided in separate high-resolution EPS or TIFF files and should not be embedded in a Word document for best quality reproduction in the printed publication. Journal quality reproduction will require gray scale and color files at resolutions yielding approximately 300 ppi. Bitmapped line art should be submitted at resolutions yielding 600-1200 ppi. These resolutions refer to the output size of the file; if you anticipate that your images will be enlarged or reduced, resolutions should be adjusted accordingly. All print reproduction requires files for ful-color images to be in a CMYK color space. If possible, ICC or ColorSync profiles of your output device should accompany all digital image submissions. All illustration files should be in TIFF or EPS (with preview) formats. Do not submit native application formats.

Software and Format . Microsoft Word is preferred, although manuscripts prepared with any other microcomputer word processor are acceptable. Refrain from complex formatting; the Publisher will style your manuscript according to the journal design specifications. Do not use desktop publishing software such as PageMaker or Quark XPress. If you prepared your manuscript with one of these programs, export the text to a word processing format. Please make sure your word processing program's "fast save" feature is turned off. Please do not deliver files that contain hidden text: for example, do not use your word processor's automated features to create footnotes or reference lists.

Article Types

- **Research Articles** . Research articles may include quantitative or qualitative investigations, or single-case research. They should contain Introduction, Methods, Results, Discussion, and Conclusion sections conforming to standard scientific reporting style (where appropriate, Results and Discussion may be combined).

- **Review Articles** . Review articles should focus on the clinical implications of theoretical perspectives, diagnostic approaches, or innovative strategies for assessment or treatment. Articles should provide a critical review and interpretation of the literature. Although subdivisions (e.g., introduction, methods, results) are not required, the text should flow smoothly, and be divided logically by topical headings.
- **Brief Reports** . Abbreviated reports will be considered, and are especially encouraged if they involve: 1) replications; 2) replication failures; 3) well-designed clinical trials and other studies with negative findings; 4) potentially interesting serendipitous findings or results obtained by post-hoc hypotheses; or 5) Dissertations in Brief (DIB). DIB is intended to encourage students to submit innovative research conducted during the student's graduate studies. It is expected that DIB manuscripts would be submitted by the student, who would be the first author. All Brief Reports should contain an abstract and provide a concise synopsis (12 manuscript pages or less) of the major findings presented in the study. The format of manuscripts submitted for Brief Reports may adhere to the Research Report or Review Article format as appropriate. Authors of Brief Reports should make available a full description of method and statistical analyses with a report of all data and information needed for meta analyses. Brief Reports should include explicit statements of limitation, and power analyses may be necessary.
- **Commentaries** . Occasionally, the editor will invite one or more individuals to write a commentary on a research report.
- **Editorials** . Unsolicited editorials are also considered for publication.
- **Notes From the Field** . Notes From the Field offers a forum for brief descriptions of advances in clinical training; innovative treatment methods or community based initiatives; developments in service delivery; or the presentation of data from research projects which have progressed to a point where preliminary observations should be disseminated (e.g., pilot studies, significant findings in need of replication). Articles submitted for this section should be limited to a maximum of 10 manuscript pages, and contain logical topical subheadings.
- **News and Notes** . This section offers a vehicle for readers to stay abreast of major awards, grants, training initiatives; research projects; and conferences in clinical psychology. Items for this section should be summarized in 200 words or less. The Editors reserve the right to determine which News and Notes submissions are appropriate for inclusion in the journal.

Editorial Policy

Manuscripts for consideration by the ***Journal of Clinical Psychology*** must be submitted solely to this journal, and may not have been published in another publication of any type, professional or lay. This policy covers both duplicate and fragmented (piecemeal) publication. Although, on occasion it may be appropriate to publish several reports referring to the same data base, authors should inform the editors at the time of submission about all previously published or submitted reports stemming from the data set, so that the editors can judge if the article represents a new contribution. If the article is accepted for publication in the journal, the article must include a citation to all reports using the same data and methods or the same sample. Upon acceptance of a manuscript for publication, the corresponding author will be required to sign an agreement transferring copyright to the Publisher; copies of the Copyright Transfer form are available from the editorial office. All accepted manuscripts become the property of the Publisher. No material published in the journal may be reproduced or published elsewhere without written permission from the Publisher, who reserves copyright.

Any possible conflict of interest, financial or otherwise, related to the submitted work must be clearly indicated in the manuscript and in a cover letter accompanying the submission. Research performed on human participants must be accompanied by a statement of compliance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and the standards established by the author's Institutional Review Board and granting agency. Informed consent statements, if applicable, should be included with the manuscript stating that informed consent was obtained from the research participants after the nature of the experimental procedures was explained.

The ***Journal of Clinical Psychology requires*** that all identifying details regarding the client(s)/patient(s), including, but not limited to name, age, race, occupation, and place of residence be altered to prevent recognition. By signing the *Copyright Transfer Agreement* , you acknowledge that you have altered all identifying details or obtained all necessary written releases.

All statements in, or omissions from, published manuscripts are the responsibility of authors, who will be asked to review proofs prior to publication. Reprint order forms will be sent with the page proofs. No page charges will be levied against authors or their institutions for publication in the journal. Authors should retain copies of their manuscripts; the journal will not be responsible for loss of manuscripts at any time.

Appendix B: Guidelines for authors for submission to Addiction Research and Theory

Addiction research and theory

Instructions for Authors

INTRODUCTION

Submission of a paper to *Addiction Research and Theory* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

SUBMISSION OF MANUSCRIPTS

All submissions should be made online at the *Addiction Research and Theory's* Manuscript Central site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Each paper will be read by at least two referees.

FORMAT OF MANUSCRIPTS

Manuscripts should be typed in double spacing with wide margins. Please upload an anonymous main document and a separate title page with author information.

Title page: This should contain the title of the paper, a short running title, the name and full postal address of each author and an indication of which author will be responsible for correspondence, reprints and proofs. Abbreviations in the title should be avoided.

Abstract: This should not exceed 250 words and should be presented on a separate sheet, summarising the significant coverage and findings.

Key words: Abstracts should be accompanied by up to six key words or phrases that between them characterise the contents of the paper. These will be used for indexing and data retrieval purposes.

TEXT HEADINGS All headings in the text should be set over to the left-hand margin, and the text should begin on the next line. Type first level (sectional) headings all in capitals. For second and third level headings, only the first letter of the first word should be a capital. Underline third level headings.

For example:

FIRST LEVEL TEXT HEADINGS

Second level text headings

Third level text headings

REFERENCES

Style, statistical reporting, and reference citations should conform to the American Psychologcal Association's guidelines, from the APA *Publication Manual*, fifth edition.

To conform with the APA *Publication Manual*, fifth edition, references should be alphabetized at the end of the manuscript text, in the following formats:

Kozlowski, L. T., Henningfield, J. E., & Brigham, J. (2001). Cigarrettes, nicotine, and health. Thousand Oaks, CA: Sage Publications.

Weinstein, N. (2001). Smokers' recognition of their vulnerability to harm. In P. Slovic (Ed.), *Smoking: Risk, perception, & policy* (pp. 81-96). Thousand Oaks, CA: Sage Publications.

Perkins, K. A., Donny, E., & Caggiula, A. R. (1999). Sex differences in nicotine effects and self-administration: review of human and animal evidence. *Nicotine & Tobacco Research*, 1, 301-315.

FIGURES

All figures should be numbered with consecutive Arabic numerals, have descriptive captions and be mentioned in the text. Figures should be kept separate from the text but an approximate position for each should be indicated in the margin. It is the author's responsibility to obtain permission for any reproduction from other sources.

Preparation: Figures must be of a high enough standard for direct reproduction. They should be prepared in black (india) ink on white card or tracing paper, with all the lettering and symbols included. Axes of graphs should be properly labelled and approporiate units given. Photographs intended for halftone reproduction must be high quality glossy originals of maximum contrast. Redrawing or retouching of unsuitable figures will be charged to authors.

Size: Figures should be planned so that they reduce to 10.5cm column width. The preferred width of submitted drawings is 16-21cm, with capital lettering 4mm high, for reduction by one-half. Photographs for halftone reproduction should be approximately twice the desired size.

Captions: A list of figure captions should be typed on a separate sheet and included in the typescript.

TABLES

Tables should be clearly typed with double spacing. Number tables with consecutive arabic numerals and give each a clear descriptive heading. Avoid the use of vertical rules in tables. Table footnotes should be typed below the table, designated by superior lower-case letters.

PROOFS

Authors will receive proofs (including figures) by air mail for correction, which *must* be returned within 48 hours of receipt. Authors' alterations in excess of 10% of the original composition cost will be charged to authors.

Offprints and Reprints

Offprints and reprints of articles published in Addiction Research and Theory can be obtained through Rightslink ® ./journals_reprints. Copies of the Journal can be purchased separately at the author's preferential rate of £15.00/$25.00 per copy.

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Appendix C: Interview schedule

Interview Schedule

Warm up Questions

Do you feel you have ever been the victim of stigma because of your relative's substance misuse?

- Have you ever suffered stigma for any other reason?

How would you describe this experience of stigma as a consequence of your relative's substance misuse?

- Does this stigma differ to any other kind of stigma you have experienced?
- Does it occur at certain times / in certain places or situations?
- Can you give me an example of a particular memory of feeling stigmatised because of your relative's substance misuse?
- How has it affected your behaviour, and made you feel?

What is your understanding of the word 'shame'?

Have you ever suffered shame as a consequence of your relative's substance misuse?

- Have you ever suffered shame for any other reason?

How would you describe this experience of shame as a consequence of your relative's substance misuse?

- Does this shame differ to any other kind of shame you have experienced?
- Does it occur at certain times / in certain places or situations?
- Can you give me an example of a particular memory of feeling ashamed because of your relative's substance misuse?
- How has it affected your behaviour, and made you feel?

Experiences of support from services

- What kind of support have you experienced since becoming involved with [carers group]?
- Do you feel that this has affected your levels of shame regarding your relative's misuse?
    - If so, how do you feel that this has affected your levels of shame regarding your relative's misuse?
- Have your social relationships changed at all since receiving support from [carers group]?
    - If so, how have your social relationships changed at all since receiving support from Saffron?

Appendix D: Confirmation of ethical approval from Local Ethics Research Committee

(Removed for hard binding)

Appendix E: Confirmation of ethical approval from Research and Development department of the National Health Service

(Removed for hard binding)

Appendix F: Participant information sheet

Participant Information Sheet

‘The experiences of parents of people with drug problems receiving support from family support services’

If you are the parent of a person with a drug problem, we would like to invite you to take part in a research study, which is being conducted as part of a university doctorate qualification. Before you decide, it is important that you understand the reasons for the research and what it would mean for you. Please take time to read the following information, and talk to others if you would like. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of this study

This study forms part of a doctorate qualification, and aims to generate a greater understanding of the effects of shame on parents of people with drug problems (often caused by society’s attitudes), and how this might affect experiences of social support.

Why have I been invited?

If you are the parent of a person with an illegal drug problem, it is your experiences we are interested in. We will be asking up to 10 parents to participate, whose relative with the drug problem has received treatment or support from services. Participants will also have lived with the relative within the past 6 months, and be currently receiving support from ‘[redacted]), the families and carer’s support component of ‘[redacted]). Participants may also be receiving support from any other drugs agency. The invitation will come from your key worker who will be in contact with the researchers.

Do I have to take part?

Participation in this study is voluntary, and if you do decide to take part, you will have the right to withdraw at any time, without giving a reason. This would not affect the standard of care you receive. The study will be described to you, by the researcher who will answer any questions you have and make sure you have a copy of this form to keep. You will then be asked to sign a consent form to show you have agreed to take part before beginning the study.

What will happen to me if I take part?

A convenient time for an interview will be arranged between you and the researcher, and your key worker may help with arranging this. Interviews will take place on [redacted] premises between normal working hours, and will last for about an hour. You will be asked to talk about your experiences of being a parent of someone with drug problems. Interviews will be recorded using a digital voice recorder and the researcher may take notes. Participant will be given a small gesture of thanks for their time and effort. You will not be contacted again unless this is individually desired and arranged with the researcher.

What are the possible disadvantages of taking part?

There is a risk that questions asked during the interview might bring painful memories to the surface for you. If this is the case, you will be encouraged to contact your key worker at CDP after the interview, if you have experienced any distress as a result of what you have talked about.

What are the possible benefits of taking part?

Though this study is not designed to help you directly, some people have found the process to be beneficial in enabling them to vent their feelings. You will also be contributing to research into the effects of drug problems on parents. This aims to benefit them by providing an understanding of the difficulties facing them, in order to deliver the best possible support services.

Will my taking part in the study be kept confidential?

All information you provide will be kept confidential, unless it is deemed necessary to share information with an appropriate support agency ('[redacted]') due to significant concerns being raised. Identifiable information will be kept in a locked filing cabinet, and only the researcher will have access to it. No identifiable data will be quoted in the study. The researcher will replace identifiable information with numbers when audio recordings are transcribed. If you decide to withdraw part way through the study, all your information will be deleted. After the study is completed, all identifiable_information will be deleted or shredded.

What will happen to the results of the study?

The results of the study will be presented in a thesis and published reports. You will not be personally identifiable by any of the information which is published. If you would like to know where you can obtain a copy of published reports, please contact the [redacted] after Oct 2009

Who has reviewed the study?

This study has been reviewed and approved by the research group at the clinical psychology department, University of Hull. As an NHS funded project, it has also been reviewed by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by: Hull & East Riding Research Ethics Committee.

Contacts

Should you require more information about the study, please contact Emma Crick at E.Crick@psy.hull.ac.uk. If you have a concern about any aspect of the study, you should contact the researchers who will do their best to answer your questions (Ms Kerry Smith, [redacted]). However, if you have concerns and wish to complain formally, you can do this through the NHS complaints procedure by initially contacting Ms Kerry Smith on the number indicated above for the communication of concerns.

Appendix G: Participant consent form

Consent Form

Centre No:

Study No:

Patient Identification No:

Title of project: **Experiences of shame and social support among parents of drug misusers**

Name of researcher: Emma Crick Please Initial Box

1. I confirm that I have read and understand the information sheet dated............ (version) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. ☐
2. I understand that my participation is entirely voluntary, that I am free to withdraw at any time, without consequence and without giving any reason. ☐
3. I agree to having the interview audio recorded on a digital voice recorder, and the possible use of unidentifiable verbatim quotation from the recordings detailed in the written study. ☐
4. I agree to completing a ‘Beck Anxiety Inventory’ and a ‘Beck Depression Inventory’ which will measure my current levels of depression and anxiety ☐
5. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix H: Demographics form

Personal Information Sheet.

Name:

Age:

Gender:

Employment status (please circle) : Employed Unemployed

Length of time you have been receiving support:

Type of support received from services (please circle as many as apply to you): Telephone support / talking directly to one person / group support

Number of residents in household:

Relationship to misuse (e.g. mother / father / step mother etc):

Length of time relative has misused:

Which type of illicit drug(s) does your relative have a problem with (if known)?

Which services have given your relative help either currently or in the past?

Dates Services / organisations (or other details)

–

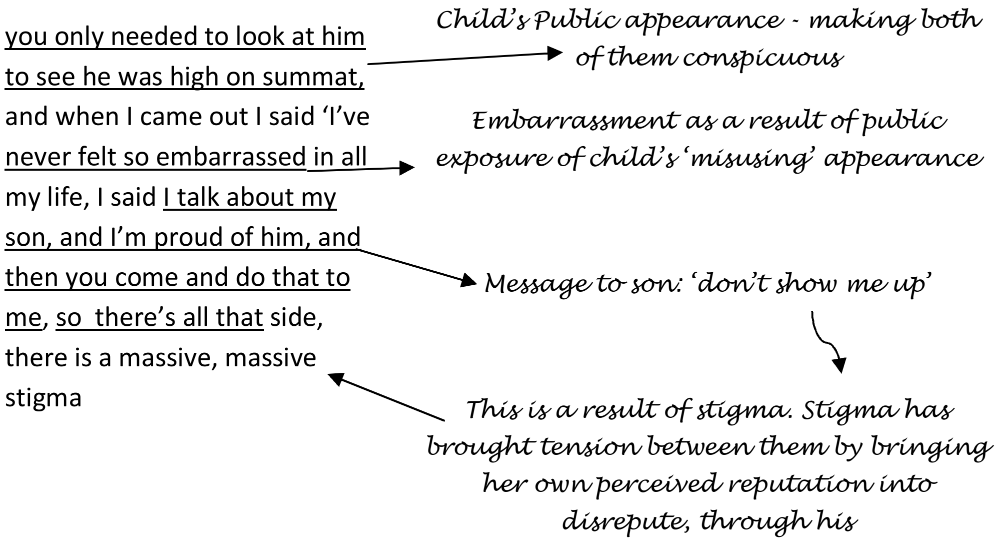
–

–

Appendix I: Sample of IPA Analysis

Sample of IPA analysis

The process began with making initial notes against the text. This could entail anything from the author's own impressions and feelings, to more objective comparisons with other aspects of the text or the relevance of theory and literature (Smith, 2003). An example is shown below:



you only needed to look at him
to see he was high on summat,
and when I came out I said 'I've
never felt so embarrassed in all
my life, I said I talk about my
son, and I'm proud of him, and
then you come and do that to
me, so there's all that side,
there is a massive, massive
stigma

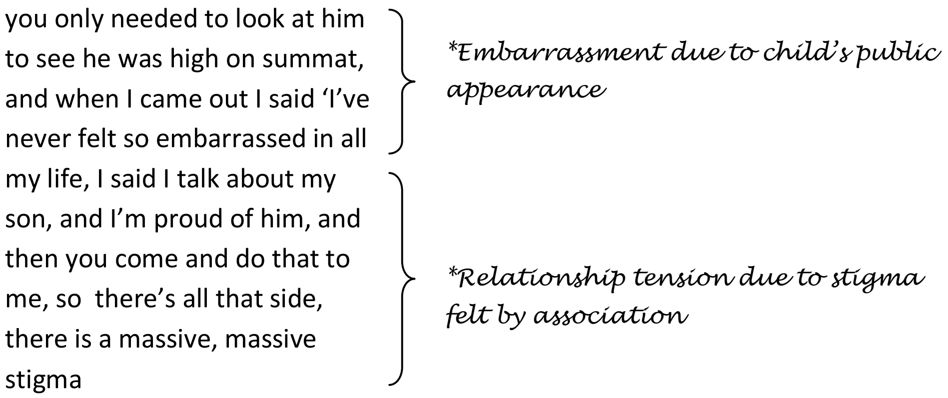
Child's Public appearance - making both of them conspicuous

Embarrassment as a result of public exposure of child's 'misusing' appearance

Message to son: 'don't show me up'

This is a result of stigma. Stigma has brought tension between them by bringing her own perceived reputation into disrepute, through his

At the second stage of analysis, transcripts are re-read and notes are grouped into smaller themes. For example:



you only needed to look at him
to see he was high on summat,
and when I came out I said 'I've
never felt so embarrassed in all

**Embarrassment due to child's public appearance*

my life, I said I talk about my
son, and I'm proud of him, and
then you come and do that to
me, so there's all that side,
there is a massive, massive
stigma

**Relationship tension due to stigma felt by association*

As each transcript was initially themed, the ATLASti software programme used was accumulating a database of all themes across transcripts, with corresponding qoutations. This meant that transcripts themed later often yielded less new themes, since notations could be adequately described by existing ones. Quotations associated with these themes could be consulted in order to confirm the appropriateness of applying them to new sections of text and thus grouping them together semantically.

When initial coding across transcripts was accomplished, the developed database of codes was cross-referenced again against earlier transcripts in order to ensure that each transcript was analysed with the benefit of an overview of all themes. The sparseness of new theme development observed provided an indicator of theme saturation, and enabled the researcher to be satisfied with the amount of data collected.

The next phase of analysis involved grouping the themes together in terms of sematic value and prevalence. The benefit of using ATLASti software was that it provided a convenient index of how many quotes (initial notations) were included in each theme, and which transcripts contained these themes. Thus, the prevalence of themes could be reliably assessed. Smaller themes were then grouped beneath larger themes of similar semantic value, and subordinate themes were created. Some themes were re-worded at this stage, with close attention paid to the sources of their meaning in quotations attached. Re-visiting quotations was a repetitive, integral part of each process. ATLASti also provided a facility in which themes could be arranged spatially in terms of their relationship to other themes, and this aided the amalgamating process greatly.

Finally, super-ordinate themes were derived from the semantic groupings of sub-ordinate themes. Again, this stage was validated by returning to the original text and ensuring that conclusions were consistent with initial convictions and an overall perspective process, including the interviews themselves within the data collection phase.

Appendix J: Participant and expert validation

Participant and expert validation

One of the mothers who had participated in the study agreed to meet with the researcher in order to discuss a sample of her transcript and the researcher's analysis of it. This mother also agreed for the leader of the group, staff of the family support service and a parent of a misuser herself, to offer her expert views on this sample. This was done in order to provide the researcher with an appropriate gauge of the validity of her derivations so far.

The meeting consisted of the researcher, parent, and group leader together. The researcher had pre-prepared a sample of the participant's transcript with annotations transcribed from ATLASti software as it exited in the programme. On a separate sheet were themes that had been developed from these annotations, and a description of how these themes had contributed to the constitution of further subordinate and super-ordinate themes.

Both parent and group leader took time to read over the sample and annotations. This provoked discussion of the content through providing material for reminiscence of what the parent had been experiencing at the time. As a result of this, she re-iterated some of the anger and concern she had expressed at interview. This served to strengthen corresponding themes, and to assist the researcher by providing an indication of what the most important themes to the participant were. With the benefit of hindsight, she was able to summarise the main things she had wanted to communicate at the time.

The parent was generally in agreement with how themes had been derived and with the appropriateness of initial notations. The group leader was subsequently able to offer her concurrence with this. Themes which were not in accordance with the new summarised structure were subsequently re-organised.

The process described above was helpful in giving the researcher some hints as to where some of her interpretative biases may lie, and this initial editing could then be applied to how other transcripts had been analysed. However, care was taken to ensure that themes from this transcript would not override others due to their increased salience as a result of the meeting.

Appendix K: Reflective statement

Reflective statement

Making conclusive reflections on my first notable experience of conducting research has highlighted how much learning has taken place. Taking in the span of the journey; from the conception of ideas and preliminary literary contact, to the present moment, the contrast in my own understanding at start and at finish is surprising.

I have become aware of the facets of my character as well as intellect that are, and are not conducive to research of different orientations. When next undertaking a research project, regardless of its scale and significance, there are broad considerations as well as more detailed ones that I will have the benefit of applying.

Broadly, I will ensure that I begin with as wide an understanding as possible of the field I am researching. An inevitable outcome has been that I am now much more able to comment knowledgeably on the areas of research most appropriate to the field I have studied, than when I began. However, this has pointed out preparations that could be indulged in with more time and confidence in order to circumvent this inconsistency in the future. I am also now much better aware of sources of knowledge to tap, and have the skills to do so.

Additionally, remaining consistently conscious of the foundations for the research project may serve to contain wandering ideas and provide an economical measure against which to assess incoming information for relevance and application.

The finer points for future reference include defining a robust argument early on in the discovery of new concepts as to their definition, scope, and relationship to other variables of interest. Discovering new terms and synonyms for subjects under scrutiny later in the process can be very disconcerting. Reviewing a topic so subjective and hard to define that there is still no consensus as shame, has been occasionally anxiety provoking in such an objective and measurement oriented mode of research such as systematic literature reviewing.

At times it was difficult to think quantitatively and qualitatively at the same time, and this often got me in a muddle. However, the stop-start motion which characterised these mistakes served to ingrain my understanding and appreciation of both modes of research.

As well as this, I have learned that qualitative research usually makes more intuitive sense to me than quantitative; perhaps because I am a person who tends to think more on an individual level, than a global one in the context of mental health, and perhaps because my intellectual strengths do not lie in the complexities of statistical analyses!

However, conducting qualitative research has entailed a personal responsibility for rigour which is very different to those of quantitative procedures, and probably more personally taxing. Apart from the extensive familiarising with data, cross-referencing and amalgamating of excerpts and themes that is necessary for a thorough analysis, there were also my own views to negotiate with. I found myself constantly stepping back in order to ‘bracket’ views, emotions or memories of my own which arose from listening to parents speak. This was sometimes quite a monotonous and exhausting task, but I felt liberated by the permission of IPA to be aware my biases, and not try to change them, but put them aside as I sought to represent parents’ language as it was meaningful to them.

These biases, as I am aware of them are chiefly a result of having personal contact with individuals stigmatised by association with a substance misusing significant other, and the injustice this entailed from my perception, having known these individuals to be entirely unworthy of such derision and disadvantage. Perhaps there is a part of me that felt it was in some small way righting some wrong, in choosing to attempt to facilitate the communication of experiences which those concerned, hope will be understood by others outside of their own marginalised group.

These experiences were thus an impetus for the chosen research course. For the voices that the participants of this study hope will be heard in some way I have developed the desire to persevere until I have done the best research that I can. From my supervisors I have been guided as to how this might be possible, and shown the nuances of my strengths and weaknesses, as well as the more obvious.

The initial formulation of a research proposal was probably the stage of the process which was most testing, and most productive of learning. It involved the unsteady and often uncomfortable process of learning to trust and submit to facts that were better understood by others. I am grateful to that stage of defeat and discovery not only for the relative ease which followed it, but for the growth it afforded me. I was learning about research, but I was also learning about communication.

This is appropriate, and perhaps not surprising considering the methodology I have chosen to work with, with its philosophical roots in how people communicate and make meaning through language.

Every stage of the process has involved the acquisition of new skills in communication. In order to make steps forward it is necessary to communicate effectively with academic supervisors, participants, authors of research, staff of organisations, participants, ethics committee members, the unknown readers of one’s potential journal article, as well as relatives and friends who become defaulted parties to the endeavour, and make many small sacrifices, adding up to large ones, along the way.

Justification for choice of journals

I have chosen to prepare my systematic literature review according to guidelines for submission to the Journal of Clinical Psychology. The main reason for this was that the study has produced clinical implications for mental health service development, and clinicians who run support groups (of which clinical psychologists are included). The Journal is also well-known, with a high impact factor; a likely sign of its quality, and it is peer reviewed.

For the submission of my empirical study I have chosen to apply the guidelines for the journal: Addiction, Research and Theory. This journal is one of the most psychologically oriented peer reviewed journals in addiction research, which regularly publishes qualitative literature. It is recommended by the leading investigator in the field of families and addiction: head of the ‘Alcohol, Drugs and the Family Research Group’; Professor Jim Orford. It also contains material from a range of disciplines; for whom my study has produced clinical implications.