Family and Individual Experiences of Self Detoxification Processes in the Mid West.

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2012

MWRDTF Chairperson's Foreword

The Mid West Regional Drugs Task Force has a broad co-ordination remit in relation to substance misuse. This includes education and prevention to treatment and rehabilitation; to supply reduction and research in the region (Clare, Limerick City & County and North Tipperary).

For some time, Individuals, Families and Communities have highlighted the need for access to detoxification and in various ways, the MWRDTF; statutory and voluntary services have attempted to respond to these demands.

Therefore, the research proposal from Researchers, Dr. Marie Claire Van Hout and Tim Bingham, to research this particular area was most welcomed by the MWRDTF. This research would enhance our understanding of the experience of home detoxification, from both the individuals and family member's perspective. It has also provided the Task Force a basis, for moving forward, with our partner organisations, to address the concerns and issues identified by this piece of research.

The research specifically focussed on the experience of the individual and the family member, and this is reflected in the recommendations which come from that experience (and without any service providers input). In doing this it has highlighted a number of safety issues plus the lack of knowledge and support for people and families who home detoxify.

The MWRDTF and its partner organisations would like to draw your attention to the fact; that at the same time as this research, engagement has been made with Progression Routes on the National Community Detoxification Initiative which promotes safer, accessible options for those seeking to reduce their methadone or benzodiazepine use. The Progression Routes Initiative is currently being rolled out to a number of national pilot sites in 2012, one of which is in the Mid-West. It is anticipated that the Progression Routes Initiative will commence to address some of the important recommendations of this research report.

The report also makes a number of recommendations in relation to 'Information Provision' which clearly indicates that while services may be available, they are not necessarily known to the people that need them at the time they need them. This is something that the MWRDTF and its partner organisations will strive to address, along with the other recommendations made in this report.

We would like to offer our sincere appreciation and thanks to all those concerned with facilitating, participating and delivering this research. We would like to thank all those individuals and family members who participated in the study for sharing their experience so candidly. We would also like to thank the organisations who linked the participants to the Researcher, without whose support this report would not have been possible.

Mick Lacey, Chairman, Mid West Regional Drugs Task Force May 2012

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Executive Summary

Background to Research

An effective treatment system for drug and alcohol dependence requires the availability of detoxification to individuals, in the context of provision of managed withdrawal (Gowing *et al.*, 2000a;b). Detoxification, in the context of drug and alcohol treatment has been defined as follows; "*a set of interventions aimed at managing acute intoxication and withdrawal. Supervised detoxification may prevent potentially life-threatening complications that might appear if the patient was left untreated.*" (Centre for Substance Abuse Treatment (CSAT), 2006:4). Research highlights the presence of individual strategies and attempts to achieve abstinence, which include self-detoxification attempts without formal medical assistance and/or with the help of drugs and/or alcohol (Gossop *et al.*, 1991; McElrath, 2001a; b; Noble *et al.*, 2002; Ison *et al.*, 2006; Peterson *et al.*, 2010; McDonnell and Van Hout, 2010; 2011). Detoxification and the achievement of abstinence is possible without formal treatment (Ward et al, 1999, Bobrova et al, 2006, Ison et al, 2006, Bobrova et al, 2007), and is often preferred with community based supports from local General Practitioners, family and other users (Hartnoll, 1992, McElrath, 2001a; b, Appel et al., 2004, Hopkins & Clark, 2005, Grella et al., 2009).

The need for an increase in community and residential detoxification services in Ireland has been articulated at national and local level (Mannix, 2006; Dept. Community, Rural and Gaeltacht Affairs, 2007; Corrigan and O'Gorman, 2008; Doyle and Ivanovic, 2010; McDonnell and Van Hout, 2010; McDonnell and Van Hout, 2011). Several Community Detox protocols and initiatives have been developed in Ireland (Department of Health and Children, 2002; Barron, 2005; National Drug Rehabilitation Framework; Doyle and Ivanovic, 2010; Regional Drug Coordination Unit HSE Mid-West, 2010; Progression Routes Initiative (PRI), 2011a;b). There is a dearth of research on individual and family experiences of the self detoxification process (Ison et al., 2006; McDonnell and Van Hout, 2011). Irish research conducted by McDonnell and Van Hout (2010; 2011) with a sample of opiate dependents observed that family members are often involved in the sourcing of information on treatment options, assisting in treatment access and uptake, user advocacy and the provision of remedial supports whilst detoxifying within the family home. There is a need for further research into the area of family experiences of self detoxification, so as to inform the development of local and regional community detoxification supports and interagency protocols (Orford et al., 2005a;b; Anderson, 2010; Harris, 2010; Pike, 2011; Harwin et al., 2011; EMCDDA, 2011; McDonnell and Van Hout, 2011; Orford, 2012). Indeed, research has emphasised how the current base of treatment provision must diversify to include the family and the home setting as "legitimate unit for intervention" (Copello et al., 2005:1361). Therefore, the aim of the research was to describe family and individual participants' experiences of self detoxification processes both within the home and hostel settings using a phenomenological approach.

Research Methodology

Ethical approval for the study was granted by the Health Service Executive at Waterford Regional Hospital in January 2012. Several consultative meetings were held between the researchers, and the both Treatment and Rehabilitation sub group of the Mid West Regional Drugs Task Force (MWRDTF) and representatives from voluntary and statutory groups who collectively formed a Research Advisory Group (RAG). The RAG was

consulted in order to finalise the research objectives, clarify issues around gatekeeping and participant recruitment, interview guides and ethical protocols around participation in a series of interviews. The RAG along with the MWRDTF assisted in recruitment of participants across the Mid West Region (see Appendices). A convenience sample of adult family members who had experienced a family member detoxifying in the home setting (n=11) and adult individuals who had experienced self detoxification in the home and whilst homeless (n=10) partook in the research. Long and in-depth phenomenological based interviews (Creswell 1998; Boyd, 2001) were conducted in February and March 2012. The interview questions centred around individual and family experiences and perspectives around self detoxification processes, levels and accessing of general practitioner and formal treatment supports, and recommendations for improved community detoxification supports in the Mid West Region. The phenomenological approach aimed to describe and garner rich understanding of social and psychological phenomena as experienced by the participants themselves and derived from their perspectives around individual, child or partner experiences of self detoxification.

Results

Definitions of Detoxification

A variety of definitions of detoxification were described, which centred on the physical process of '*comedown*' and withdrawal from licit and illicit substances and the achievement of abstinence. Several family participants also described self detoxification as pre cursor to treatment uptake and opportunity for drug and alcohol rehabilitation.

Substances Used

A variety of dependent or problematic substances were described by family and individual participants, and which included alcohol, heroin, cannabis, cocaine, over the counter codeine and prescribed medication. Efforts to self detoxify were complicated by the presence of problematic poly drug taking patterns, and the use of certain substances to counter act unpleasant withdrawal symptoms, and replace harmful drug use with less serious (perceived) forms of substance use. Examples included the use of alcohol, cannabis, and anti anxiety medication (prescribed and street sold) to manage opiate withdrawals (both heroin and over the counter codeine) and cocaine cravings. In some instances, use of heroin, cannabis and cocaine was self medicated in an attempt to counteract the effects of prescribed medication. Some family participants described getting alcohol for family members in order to help pacify unpleasant withdrawals. The presence of these drug displacement patterns used in self detoxification to self medicate was observed by some participants to contribute to occurrence of mental health issues such as psychosis, suicidal ideation and aggressive behaviours, and development of new drug dependencies.

Self Medication

Some general practitioners were observed to provide little information around the safe detoxification from substances at home, and only in some instances prescribe anti nausea and anxiety medications. Only some general practitioners offered advice around the safe use of prescribed medication whilst detoxifying. Several family participants described a lack of knowledge around the safe administration of prescribed medication used to manage withdrawals. The dangers of self detoxification using self medication, and the management of withdrawals with prescribed medication, alcohol and illicit drugs were described by both individual and family participants. Several parents described purchasing

illicit drugs such as cannabis and anti anxiety medication (Xanax, Zimovaine, DF118s) on the street, in order to medicate their child through the withdrawal period, and attempted to monitor the safe consumption of these substances. A lack of knowledge was described by family and individual participants with regard to the safe tapering of certain drugs such as methadone, prescribed medication and alcohol. A majority of family participants described negative health outcomes from prescribed medication dependence which included *'benzo'* seizures. Two individual participants described the effect of prescribed medication dependency and reoccurring *'benzo'* seizures. Several family participants described difficulties in tackling benzodiazepine dependency following home detoxification, and attempts to then access residential treatment. The dependence on prescribed medication was observed to impact negatively on residential treatment uptake, exacerbated anxiety and depression, and necessitated medically supervised detoxification.

Methadone Maintenance Treatment

Both the unsupervised self detoxification from methadone, and the self detoxification from heroin, so as to avoid methadone maintenance treatment were described by family and individual participants. Peer and individual reporting underscored that coming off methadone was more difficult than heroin. As a result, several individual and family participants described refusing to commence methadone maintenance treatment and viewed methadone as a replacement addiction. This contributed to attempts at self detoxification in order to access residential treatment.

Life Turning Points and Self Detoxification

Some individual participants described stealing from friends and family, the loss of important family relationships, overdoses, incarceration, death of drug using friends, and reaching crisis points prior to undertaking home detoxification. Similar observations were made by family participants. The relinquishing of previous addictive patterns, lifestyles and user networks were also described. One individual participant described deciding to detoxify from drugs as a life changing spiritual experience.

Stigma of Addiction and Treatment Seeking

Some family members described the stigma of having a child with an addiction. Several family participants described uncomfortable experiences when attempting to find information around treatment and detoxification, and when accessing medical and detoxification services on behalf of their children.

Detoxification Service Provision and Information Seeking

A lack of detoxification support in the region was described by family participants as stimulating home detoxification decision making and information seeking. General practitioner supports and information provision for detoxification were described as lacking. Several family participants described learning about detoxification processes from personal and peer experiences in their communities, and used the internet to find information around home detoxification. Family participants appeared responsible for seeking information on detoxification and treatment pathways.

Urine Screening, Treatment Uptake and Self Detoxification

Several family and individual participants described how attempts at self detoxification occurred in efforts to access residential treatment, where '*clean urine*' screening was an entry requirement. The inability to access formal addiction treatment whilst still using was described as contributing to suicide ideation and risk. In some instances, treatment centers accepted individuals at risk of suicide completion without the required '*clean urine*' screening.

Financial Barriers, Treatment Uptake and Self Detoxification

Financial barriers to accessing formal addiction treatment included costly assessment procedures, lack of funded places and the presence of long waiting lists for funded treatment were described as impacting negatively on uptake of formal treatment pathways and contributing to attempts at self detoxification within the home setting. Families appeared responsible for detoxification and treatment funding. Some parents described taking out large Credit Union loans in order to pay for their child's treatment (amounts of up to \notin 16,000 were mentioned) and lengthy journeys to treatment centres.

Self Detoxification Experiences

Several individual participants described unpleasant detoxification experiences which included cold sweats, shaking, insomnia, paranoia, diarrhea and nausea often lasting longer than several days. A lack of understanding of drug addiction, physical and psychological dependency and the potential risks of self detoxification were described by most family participants, and was observed to impact negatively on the care they provided to detoxifying family members. The need for specific family support in the form of medical and psycho-social assistance for those seeking to detoxify alone was described by many family participants. Some individual participants also described unpleasant experiences of detoxification, the lack of information around safe detoxification processes, the length of time needed to fully detoxify and reflected on the potential for harm in unsupervised attempts to detoxify without close medical supervision. Some individual participants questioned whether home detoxification was feasible and appropriate given the nature of addicts, and highlighted the need for professional advice and supervision.

Detoxification and the Family Bond

All family participants described the closeness of the parent and child bond in helping them to support their child's detoxification at home. The need for support from family members for those undertaking home detoxification was also underscored by some individual participants. Individual participants who were homeless at the time of detoxification described how hostel staff became like family members in providing support during the process. However, several individual participants described home and street detoxing alone and hiding their detoxification from family members. Other individual participants described how the close family bond supported them during both hidden and family supported detoxification attempts and encouraged them to endure.

Detoxification Impact on the Family

Many family members had personal experiences of detoxification, but described how supporting their children detoxify in home as extremely upsetting, which in some instances involving locking their children into rooms, neglect of other family members (usually children) and how this all consuming process impacted on the family as a whole. The impact on the family was described as devastating, and causing intense and long term suffering for family participants. The detoxification process was described as exhausting and in some cases unsuccessful. Many family members described instances of aggressive and hostile behaviour in addicted children as impacting negatively on them and their families. Family members supporting and taking care of those detoxifying described the long term mental health and family functioning implications, and underscored the need for long term support mechanisms.

Relapses and Aftercare Supports

Instances of relapse were described as frequent by both family and individual participants, who emphasised the need for timely residential treatment uptake post detoxification in the

home, the need for a safety net of support and stabilisation systems for those self detoxifying in the home, and on discharge from residential treatment facilities. Aftercare provision appeared confined to AA structures in the community. Many family participants described the cost of aftercare as prohibitive and impacting negatively on sustained abstinence post detoxification and treatment. Individual participants observed difficulties in undertaking methadone maintenance treatment and attending aftercare whilst on methadone.

Recommendations for Community detoxification service provision

Family and individual participants described the need for improved regional and local medical and psycho-social detoxification supports in the Mid West, alongside the need for improved information for families and individuals seeking to detoxify, provision of needle exchange and harm reduction services, and increased regional treatment and rehabilitation provision. Several family participants described the need for a safe place for individuals to detoxify in the community. Individual participants who has detoxified in homeless accommodation also described the need for a safe place to detoxify, which in some instances was observed to be better placed away from the family home.

Recommendations

The following are a series of key recommendations arising from the research findings. Information Provision

- 1. To highlight the National Drugs Help Line;
- 2. To produce web based and health service information that can sign post individuals seeking assistance to drug and community based services in the Mid West;
- 3. To ensure visibility of the National Community Detox information leaflet in the Mid West;
- 4. To advise services and families of the <u>www.drugs.ie</u> website which provides information on community detoxification and distribute the DVD;
- 5. To have Community Detoxification and Prescribed medication awareness workshops for drug users and their families (i.e during local drug awareness events);
- 6. To provide additional training courses with support from the PRI and the ICGP regarding awareness raising of home detoxification, the need for improved information provision and health professional involvement.

Community and Family Support

7. To develop a support group that has had experience of self and family home detoxification in conjunction with the family support services in the region and the MWRDTF.

Services

- 8. To have a low threshold drop in service to provide referral pathways to community detoxification, treatment, step down, aftercare and rehabilitation services;
- 9. To provide community detoxification within existing service provisions in the Mid West, and as described by national community detoxification protocols;
- 10. To provide a community based stabilization programme in an existing project(s);
- 11. To provide additional training on community detoxification protocols for existing staff and in conjunction with PRI;
- 12. To have adequate residential detoxification accommodation in the Mid West.

Chapter 1. Background to Research

An effective treatment system for drug and alcohol dependence requires the availability of detoxification to individuals, in the context of provision of managed withdrawal (Gowing *et al.*, 2000a;b). Detoxification, in the context of drug and alcohol treatment has been defined as follows; "*a set of interventions aimed at managing acute intoxication and withdrawal. Supervised detoxification may prevent potentially life-threatening complications that might appear if the patient was left untreated.*" (Centre for Substance Abuse Treatment (CSAT), 2006:4). Detoxification as initial starting point along the treatment pathway involves a graded and controlled reduction of tolerance, in conjunction with the medical management of unpleasant withdrawal symptoms (Wesson and Ling, 2003). Methods of drug and alcohol detoxification have developed over time, to "reflect a more humanitarian view of people with substance use disorders" (CSAT, 2006:3).

Medically supervised detoxification involves a doctor and/or nursing staff administering medication to help and support individuals through the safe physical withdrawal from drugs and alcohol. Detoxification methods are based on the general rule that an intense short-lived withdrawal (measured in terms of days) will precede a milder longer one (lasting weeks to months) and is achieved by using medications that target withdrawal-induced sympathetic activity (i.e. alpha-2 adrenergic agonists such as clonidine and lofexidine), those which exert a cross tolerance effect in the case of opiate dependence (i.e. long-acting µ-receptor agonist methadone and µ-receptor partial agonist buprenorphine), and symptomatic medications which relieve withdrawal symptoms (i.e. benzodiazepines, anti-diarrhea drugs, sedative-hypnotics, anti-emetics, non-steroidal anti-inflammatory and nausea drugs (Kleber, 1999). There is generally a mixture of formal medically supervised approaches found in detoxification programmes (Mattick and Hall, 1996; Robertson and Wells 1998; Inkster and Matheson, 2001; Keen *et al.*, 2001; Rae *et al.*, 2001; Ghodse *et al.*, 2002; Gossop *et al.*, 2003).

Research highlights the presence of individual strategies and attempts to achieve abstinence, which include self-detoxification attempts without formal medical assistance and/or with the help of drugs and/or alcohol (Gossop *et al.*, 1991; McElrath, 2001a; b; Noble *et al.*, 2002; Ison *et al.*, 2006; Peterson *et al.*, 2010; McDonnell and Van Hout, 2010; 2011). Self-detoxification has been defined as a deliberate attempt to become abstinent from drugs or

alcohol without formal medical detoxification or without the supervised provision of medication (Gossop et al., 1991; Noble et al., 2002). In particular, self detoxification attempts are frequent in opiate dependent populations (Noble et al., 2002; Dennis et al 2005; Hopkins & Clark, 2005; Ison et al., 2006), with a majority of opiate dependents remaining on the periphery of treatment systems (Gossop et al, 1991; Guggenbuhl et al., 2000; Friedman et al., 2004; Bobrova et al., 2006; 2007; Petersen et al., 2010). Research shows that detoxification and the achievement of abstinence is possible without formal treatment (Ward et al, 1999, Bobrova et al, 2006, Ison et al, 2006, Bobrova et al, 2007), and is often preferred with community based supports from local General Practitioners, family and other users (Hartnoll, 1992, McElrath, 2001a; b, Appel et al., 2004, Hopkins & Clark, 2005, Grella et al., 2009). Of interest for this research is that the presence of individual and familial factors supporting detoxification, treatment decision making and treatment uptake include the user's mindset and readiness for treatment, the presence or absence of supportive family members, supportive community relationships and life changing events (Glaser and Strauss, 1967, Power et al, 1992; Hartnoll, 1992, McElrath, 2001a, Hopkins & Clark, 2005, Bobrova et al, 2007, Neale et al 2007b).

Within the Irish context, the need for an increase in community and residential detoxification services has been articulated at national and local level (Mannix, 2006; Dept. Community, Rural and Gaeltacht Affairs, 2007; Lyons, 2008; Corrigan and O'Gorman, 2008; Doyle and Ivanovic, 2010; McDonnell and Van Hout, 2010; McDonnell and Van Hout, 2011). A report from the statutory Working Group on Rehabilitation stated that, "*clients often feel that they are not given adequate options regarding their treatment and care-plans......this is particularly evident to detoxification*" (Dept. Community, Rural and Gaeltacht Affairs, 2007:35). Discussions around inter agency community detoxification in Ireland using UK best practice guidelines commenced in 2008 and aim to create drug user ownership of detoxification and treatment pathways (Lyons, 2008). Several Community Detox protocols and initiatives have been developed in Ireland (Department of Health and Children, 2002; Barron, 2005; National Drug Rehabilitation Framework; Doyle and Ivanovic, 2010; Regional Drug Coordination Unit HSE Mid-West, 2010; Progression Routes Initiative (PRI), 2011a;b). The Community Detox Protocols are a set of guidelines for key workers and doctors to support community-based out-patient detoxification from benzodiazepines or methadone. These

protocols were originally developed in response to identifiable community detoxification needs and a lack of structured community supports (Lyons, 2008). They outline the minimum medical and psycho-social supports (weekly relapse prevention, care planning, regular medical appointments) necessary for individuals to engage in interagency community detoxification, and also clarify the role of each stakeholder in the process (service user, GP and key worker) (Progression Routes Initiative (PRI), 2011a;b). Of interest is the distinction between methadone and benzodiazepine into clear protocols relating to risks, processes, structural contexts for prescription and detoxification. Also, the detoxification process has been structured into four steps called brokering, preparation, detoxification and aftercare. Guidelines, information and resources for prescribing doctors, and a FAQ section for service users and their families are also included.

The protocols were originally developed by an interagency group which includes representation from service user groups, research bodies, and medical, community and voluntary service providers in 2007. Community detoxification supports aiming to provide an alternative for individuals with family and/or work commitments, or those wishing to reduce methadone dosage in order to access residential treatment were piloted in the North Inner City Drugs Task Force (NICDTF) area of Dublin from 2007 – 2009. Staff from Progression Routes Initiative acted in the role of broker, and continues to do so. An evaluation indicated promising levels of engagement, retention and satisfaction from service users, doctors and key workers. The initiative is still running in the North Inner City with approximately 4-6 referrals per month. In November 2010, the Community Detoxification Steering Group reconvened and was expanded.

These national Community Detox protocols are endorsed by the Health Service Executive and are currently being implemented across eleven different Task Force regions with support from a high level multi agency expert steering group. After successfully piloting the protocols in Dublin's North Inner City, nine additional local or regional areas across Ireland have begun to implement the protocols in 2012. The National Community Detoxification Pilot 2012 was officially launched at the National Drugs Conference of Ireland in 2011. The areas include: The Southern Region (Cork / Kerry), the South Eastern Region, The Midlands, the North Eastern Region, the Mid West Region, Dublin: North Inner City, South

Inner City, Ballymun, Ballyfermot, Bray. In each of the pilot areas, a local broker has been nominated by each local or regional drugs task force to be trained (by PRI) and to support engagement from service users, doctors and community drug services. The role of the broker is to support engagement of GPs and community based addiction workers in outpatient detoxification. Professionals from a variety of roles have undertaken brokering in the various pilot sites including Drugs Task Force Development Workers, Rehabilitation Coordinators, Community Voluntary Service Workers, GPs, Nurses etc. An evaluation will be conducted with the support of the evaluation sub group in 2012. Lastly, in terms of key staff training, the PRI has worked together with the Irish College of General Practitioners (ICGP) on general practitioner (GP) training courses, and the Community Detox Steering group is assisting the PRI and the Learning Curve in developing a training package for staff upskilling in Relapse Prevention. An information leaflet approved by the national community detoxification steering group is available in areas that engage with national protocols. In addition, a web page devoted to community detoxification and describing home detoxification can be accessed, supported and provided, including a short DVD for service users and family members may be viewed on <u>www.drugs.ie</u>.

In general, there is a dearth of research on individual and family experiences of the self detoxification process (Ison *et al.*, 2006; McDonnell and Van Hout, 2011). Irish research conducted by McDonnell and Van Hout (2010; 2011) with a sample of opiate dependents observed that family members are often involved in the sourcing of information on treatment options, assisting in treatment access and uptake, user advocacy and the provision of remedial supports whilst detoxifying within the family home. The current base of treatment provision must diversify to include the family and the home setting as "*legitimate unit for intervention*" (Copello *et al.*, 2005:1361). Despite positive efforts in the piloting, implementation and provision of community detoxification supports, debate on national protocols, service level agreements and rehabilitation pathways continues in Ireland (Shanks, 2002; Irish Medical Times, 2010, Keane, 2011; D áil Debates January 11th 2012). The need for further research into the area of family and individual experiences of self detoxification, so as to inform the development of local and regional community detoxification supports and interagency protocols has been quoted in the existing literature (Orford *et al.*, 2005a;b; Anderson, 2010; Harris, 2010; Pike, 2011; Harwin *et al.*, 2011; EMCDDA, 2011; McDonnell

and Van Hout, 2011; Orford, 2012). Therefore, the aim of the research was to describe family and individual participants' experiences of self detoxification processes using a phenomenological approach.

Chapter 2. Research Methodology

Ethical approval for the study was granted by the Health Service Executive at Waterford Regional Hospital in January 2012. General ethical principles of the Economic and Social Research Council were adhered to throughout all research phases [ESRC Research Ethics Framework: pp22-26]. Several consultative meetings were held between the researchers, and both Treatment and Rehabilitation sub group of the Mid West Regional Drugs Task Force (MWRDTF) and representatives from voluntary and statutory groups who collectively formed a Research Advisory Group (RAG). The RAG was consulted in order to finalise the research objectives, clarify issues around 'gatekeeping' and participant recruitment, design of interview guides, and ethical protocols around participation in a series of interviews (see Appendices).

The RAG along with the MWRDTF assisted in recruitment of participants across the Mid West Region. A convenience sample of adult family members who had experienced a family member detoxifying in the home setting (n=11) and adult individuals who had experienced self detoxification in the home and whilst in hostel accommodation (n=10) partook in the research. Snowball sampling (Crabtree and Miller, 1992; Babbie, 1995) was limited to two referrals from each study participant, in order to reduce bias, so as to achieve a good cross section of individual and family detoxification experiences. All participants were contacted by phone, letter and met by the interviewer to advise of the research aims and methodologies. This aimed to create a research *'friendly'* atmosphere, and created a certain level of familiarity and trust with the interviewer.

Long and in-depth phenomenological based interviews (Creswell 1998; Boyd, 2001) were conducted in February and March 2012. The interview questions centred on individual and family experiences and perspectives on self detoxification processes, accessing of general practitioner and formal treatment supports, and recommendations for improved community detoxification supports in the Mid West Region. Interviews lasted between one and two hours, and were conducted in semi public areas chosen by the participant. Information regarding research aims and objectives was repeated prior to commencement of the interview, and participants were encouraged to ask for clarification if needed throughout the research. Participants provided verbal and written consent (Kvale, 1996; Holloway, 1997), were advised of anonymity, confidentiality and permission to withdraw if they wished during the course of the study. Names and other personal or regional identifiers were not discussed or collected in order to protect the participants. All participants were allocated a code prior to interview. The interview questions were asked in conversational tone and without judgment, and were audio recorded with permission. Data saturation was reached after 21 interviews. Identifiers that inadvertently appeared in the audio taped interviews were removed within 24 hours of the interview, with tapes transcribed within several days of the interview and destroyed once transcribed.

The phenomenological approach aimed to describe and garner rich understanding of social and psychological phenomena as experienced by the participants themselves and derived from their perspectives around individual, child or partner experiences of self detoxification. 'Bracketing' in this sense involved asking the participants to describe and reflect on these experiences, both from their individual perspectives and that of their child or partner (Bentz and Shapiro, 1998; Davidson, 2000; Caelli, 2001). Some participants had personal and familial experiences of detoxification in the home. Additional researcher 'bracketing' (Miller and Crabtree, 1992) was then undertaken by both researchers to 'bracket' their preconceptions around detoxification, and enter the participant's world. The use of dated and detailed memos, and observational and analytical field notes following each interview (Miles and Huberman, 1984; Caelli, 2001), formed the initial basis for data explicitation. Interviews were listened to several times with transcripts re read several times in order to achieve a holistic sense (the 'gestalt') of the interviews (Holloway, 1997; Hycner, 1999). Extensive briefing sessions were held between researchers, with a system of inter rater corroboration assisting in the identification and analysis of emergent data patterns, delineating units of meaning (Moustakas, 1994), clustering units of meaning into themes via grouping of units of meaning, and identifying units of significance (Giorgi, 1985; De Castro, 2003), with 'outliers' analysed under conditions by which outliers could be interpreted by the research team. Finally, the interviews were validated and summarized incorporating the identified themes within the holistic (the 'gestalt') context (Hycner, 1999).

Chapter 3. Results

Eleven family participants (one brother, one father and nine mothers) who had experienced a family member self detoxifying in the home partook in the research. Two family participants had personal experience of home detoxification. In order to protect their identities, it was not possible to engage in brother/sister/father/mother analysis. Ten individuals who self detoxified whilst at home (n=5) or in homeless accommodation (n=5) also partook in the research. The combined analysis of qualitative data yielded the following themes; 'Definitions of Detoxification'; 'Substances Used'; 'Self Medication'; 'Methadone Maintenance Treatment'; 'Life Turning Points and Self Detoxification'; 'Stigma of Addiction and Treatment Seeking'; 'Detoxification Service Provision and Information Seeking'; 'Urine Screening, Treatment Uptake and Self Detoxification'; 'Einancial Barriers, Treatment Uptake and Self Detoxification'; 'Self Detoxification Experiences'; 'Detoxification and the Family Bond'; 'Detoxification Impact on the Family'; 'Relapses and Aftercare Supports' and 'Recommendations for Community detoxification service provision'.

Definitions of Detoxification

A variety of definitions of detoxification were described, which centred on the physical process of '*comedown*' and withdrawal from licit and illicit substances and the achievement of abstinence.

Its withdrawal, it's coming down off a drug, from the chemicals that your mind and your brain aren't working anymore, it's getting the stuff out of your system.' Family Participant

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Relieving the body of all traces of the substance that you're detoxing from, be it alcohol or drugs, it's to cleanse the system of that particular substance.' Individual Participant 1

Several family participants also described self detoxification as pre cursor to treatment uptake and opportunity for drug and alcohol rehabilitation.

It's somebody going into rehab, coming off all the drugs, when they come off the drugs, there is some kind of programme, where they can get their life back together or an occupation.' Family Participant 3

Detox is helping somebody to break a habit, helping them cope, giving them skills to break the habit of their addiction, and hoping that they would come out the other side.' Family Participant 6

Substances Used

A variety of dependent or problematic substances were described by family and individual participants, and which included alcohol, heroin, cannabis, cocaine, over the counter codeine and prescribed medication. Efforts to self detoxify were complicated by the presence of problematic poly drug taking patterns, and the use of certain substances to counter act unpleasant withdrawal symptoms, and replace harmful drug use with less serious (perceived) forms of substance use. Examples included the use of alcohol, cannabis, and anti anxiety medication (prescribed and street sold) to manage opiate withdrawals (both heroin and over the counter codeine) and cocaine cravings. In some instances, use of heroin, cannabis and cocaine was self medicated in an attempt to counteract the effects of prescribed medication.

When I started taking the benzos, I was waking up groggy in the morning, then I was using cocaine to counteract that, so I could function during the day, and then smoking cannabis to take the edge off that, and then more benzos at night, and that was the cycle for ages, probably for six or seven months.' Individual Participant 1

I knew myself it was going to be hell coming off it, once the money ran out for the alcohol, and once the alcohol would not stay down in my stomach, it was that or turn to tablets...what I have heard is that coming off the tablets is bad as well, I am now drinking every day of the week.' Individual Participant 2

Some family participants described getting alcohol for family members in order to help pacify unpleasant withdrawals.

It's not nice watching her and my brother shaking mad for a drink, I often have given my mother the money, she would be very sick, I am doing it because of the way she is. I don't like to look at my mother like that, so I say ok, I will get a can or two to take the shakes away, I know I am not helping.' Family Participant 1

The presence of these drug displacement patterns used in self detoxification to self medicate was observed by some participants to contribute to occurrence of mental health issues such as psychosis, suicidal ideation and aggressive behaviours, and development of new drug dependencies.

Self Medication

Some general practitioners were observed to provide little information around the safe detoxification from substances at home, and only in some instances prescribe anti nausea and anxiety medications. Only some general practitioners offered advice around the safe use of prescribed medication whilst detoxifying.

When I went to my GP, he didn't mention the word detox to me, all he said is that you need to go to a treatment centre, which is easier said than done, he never once offered me a detox, which looking back on it is shocking. I could have died at home. I spent the three days walking the floors without sleep and my head racing, its only striking me now how crazy that is.' Individual Participant 1

We basically went into it blind, we got the medication from the GP, but no information" Family Participant 7

Several family participants described a lack of knowledge around the safe administration of prescribed medication used to manage withdrawals.

Its been very hard, we didn't know what we were doing, we were at desperations door, we decided that we would have to step in, we put her on 24 hour lock down,, but we kept giving her tablets, we probably over medicated her for the first few weeks just to keep her calm because she was very, very sick, it was very frightening spasms and fits, as soon as I gave her the tablets she would vomit them back up again, I went to the stage when I was pumping her full of the tablets which I thought was something I would never do but I did, but they didn't knock her out, if I had given them to anyone else, they would probably have been in the hospital I know that now.' Family Participant 7

The dangers of self detoxification using self medication, and the management of withdrawals with prescribed medication, alcohol and illicit drugs were described by both individual and family participants.

I don't think parents are educated enough to know how to do it at home, the young fellers are self medicating when they are trying to come off stuff, and then they end up addicted to another substance, no matter what you're addicted to, you will chance your arm and swap it for another addiction.' Family Participant 4

It's through people like myself, who see the dangers of self medicating and detox yourself at home unsupervised, that when you come out the other end, you see how dangerous that is.' Individual Participant 1

Several parents described purchasing illicit drugs such as cannabis and anti anxiety medication (Xanax, Zimovaine, DF118s) on the street, in order to medicate their child through the withdrawal period, and attempted to monitor the safe consumption of these substances.

We were very frightened, we got the medication off the doctor that worked to some degree, but towards the end, I actually bought tablets just to keep her. It took about three weeks probably to get her kind of level and then had to start cutting down off the tablets. She fought every step of the way, that was 24 hour lock down, we got her down then to a normal level of a prescribed dose of medication, it took months, it took a long time and it just literally just broke us apart, she took over every part of our life. 'Family Participant 7

I found myself enabling the heroin addict by buying him weed because he was so bad, and in so much pain. I found myself going out looking for a drug dealer to get him something to take off the edge. The cannabis didn't help, he would be ok for 5 or 10 minutes and then he would start scratching and itching. When I found that it was not helping, I just cut that as well. I was trying to replace it and take away the pain for him.' Family Participant 4

A lack of knowledge was described by family and individual participants with regard to the safe tapering of certain drugs such as methadone, prescribed medication and alcohol.

'He was coming off Xanax, he just stopped, I didn't know how to cut him down, like I didn't know how to cut down from the alcohol, it was a sudden stop, so in my mind I was thinking it has to be the same.' Family Participant 4

I am not getting any support to come down off the Xanax and I don't know where to go for that support. I would like a doctor to give me a proper detox..to come down off the tablets, that would be it, I would never again take them.' Individual Participant 4

A majority of family participants described negative health outcomes from prescribed medication dependence which included *'benzo'* seizures.

'The first time I ever witnessed a benzo fit was with one of my sons. I left him on the ground and ran out of the house, because I didn't know what was happening, I knew in my head, he was not epileptic, I knew this was more than a epileptic fit. I had no idea what's happening to him. I didn't know whether to put in him the recovery position or what to do, so I ran out of the house and left him there and rang an ambulance, because I thought he was dying. It wasn't until I went down to the hospital with him, I explained he was withdrawing from medication, that's when they thought it was a benzo fit.' Family Participant 4 Two individual participants described the effect of prescribed medication dependency and reoccurring '*benzo*' seizures.

If I haven't got tablets, I am low, I don't talk, I can't eat, I can't sleep, I can't clean the house. When I have tablets, I am a different person. They want me to come off the tablets by myself completely, but its very hard because I get benzo fits, like I could be making tea one minute and then the next I could be having a fit, your whole body goes into a lock.' Individual Participant 4

I don't think the way I used any of the substances worked because I was dependant on the benzos, it really is reduction, reduction, reduction and me trying to self medicate myself. Just did not work at any level. 'Individual Participant 1

Several family participants described difficulties in tackling benzodiazepine dependency following home detoxification, and attempts to then access residential treatment. The dependence on prescribed medication was observed to impact negatively on residential treatment uptake, exacerbated anxiety and depression, and necessitated medically supervised detoxification.

He is now addicted to tablets, they sat us down and they said that unfortunately they couldn't help him [Treatment Centre] because he now needs a medical detox because he gets benzo fits. In the past 12 weeks, he has had 14 benzo seizures because he tries to come off them, he tries to detox himself but he can't, he gets the attacks... goes to the hospital, they give him oxygen come home, then he has another attack, the body is so exhausted from the attacks that he goes to his dealer and he takes them.' Family Participant 5

The DF118's that were given to her didn't really help, they didn't do anything. We had to get her down on her prescribed medication, before she was accepted into rehab, that was tough too, because they were prescribed for her and rehab would only take her in, if she were down to a certain amount and she did suffer from depression. It's like the chicken and the egg which came first, the addiction or the depression.' Family Participant 2

"There is nobody that will take him, because he is on so much prescribed medication, nobody will take him. It's ironic you have the doctors prescribing the medication, but nobody will take him I think. I feel he is obsessed with the pills, it's like another obsession, he obsessed with the medication, that's all he can talk about. There is nobody there to help... just feel so isolated and alone.' Family Participant 3

Methadone Maintenance Treatment

Both the unsupervised self detoxification from methadone, and the self detoxification from heroin, so as to avoid methadone maintenance treatment were described by family and individual participants. Peer and individual reporting underscored that coming off methadone was more difficult than heroin. As a result, several individual and family participants described refusing to commence methadone maintenance treatment and viewed methadone as a replacement addiction. This contributed to attempts at self detoxification in order to access residential treatment.

I was willing to try anything rather than putting him on a methadone programme, because learning about drug addiction, methadone to me is another drug, it's an opiate, it does the same thing, it just levels them out, they are still dependant on it and then I was told, it's harder to come off methadone, than it is to come off heroin.' Family Participant 4

I was offered to go onto the methadone programme, which I refused point blank, because methadone is only a substitute for heroin, so you're not really coming off everything, and then people say you're addicted to methadone, but you're not addicted to methadone, because you're already addicted to heroin, methadone is the same thing.' Individual Participant 6

I would not wish it on my worst enemy, coming off the methadone is 10 times worse than coming off the gear, the only reason I got off the gear, was by getting on the methadone. When I came off the methadone in the hostel, I have always been an alcoholic, I replaced the methadone with alcohol, which was 10 times worse. Individual Participant 2

Life Turning Points and Self Detoxification

Some individual participants described stealing from friends and family, the loss of important family relationships, overdoses, incarceration, death of drug using friends, and reaching crisis points prior to undertaking home detoxification. Similar observations were made by family participants. The relinquishing of previous addictive patterns, lifestyles and user networks were also described.

You have two choices in life, it's recover or die. You're only going to wind up in one of two places.' Family Participant 6

"He hit rock bottom, he had lost his child and his girlfriend, he wanted to do a home detox, we bought him to psychiatric wards, we could not get him in,, he said that he needed to go into a centre to get better, that's when he said he wanted to do a home detox." Family Participant 3 I fell out with my family, I stole from them, every chance I got, I stole from my mother... anything I could get a fix for I took. It's going to be with me for the rest of my life, you're so sick, you don't realise what you're doing, when you have a fix, then you realise what you have done and by then it's too late. All I have left is my mother and I don't want to be stealing from her. I want to detox and get off the methadone and finish with all this rubbish.' Individual Participant 3

'Spending twenty two years in prison. I lost contact with my daughter, I did it for myself and my kids, we can now sit down and talk The turning point in my life was when I came out of the Midlands prison, and I met a friend and we went down to a burnt out house, we were sitting down on rocks and we were smoking, and he trued around to me and said; This is the life isn't it, I said I came from a cell and this is not life at all, 36 years of age smoking gear in a burnt out house and didn't care who saw me'.' Individual Participant 6

One individual participant described deciding to detoxify from drugs as a life changing spiritual experience.

I was in a treatment centre. I was a heavy drinker after treatment. I attended aftercare but I didn't really change, I carried on drinking. The change for me was in a very unusual way, it was a spiritual experience, the decision to change was instant, but the change was gradual.' Individual Participant 7

Stigma of Addiction and Treatment Seeking

Some family members described the stigma of having a child with an addiction.

The stigma. It's like you're not supposed to be associated with somebody that has a drug problem or an alcohol problem. There is a lot of stigma and people ignore you. They back away from you, once they know you have a problem...it's your own fault because you're drinking or taking drugs. The stigma can be nasty too at times and they are crying out for help, after all they want is for someone to listen.' Family Participant 6

It just looked like no one was believing us, nobody saw the problem, it was hard to try and get people to take notice and say yeah he did have a problem. It was easier to try and get him to detox at home for ourselves and not to admit we had failed to a certain extent as well. Family Participant 6 Several family participants described uncomfortable experiences when attempting to find information around treatment and detoxification, and when accessing medical and detoxification services on behalf of their children.

My second son is still on heroin. I actually took him to a centre recently and I felt so belittled by the way he was treated there by the man who was taking the urine, that I swore he will never go to a place like that again, he made so little of him. I wished at those stages that he was dead and didn't have to put up with it. You cry when you get home, because they are your children and they are human beings as well.' Family Participant 9

There was a shame about going to your Doctor. I would have tried anything rather than go to my GP to say I have a son in addiction but I had to.' Family Participant 4

Detoxification Service Provision and Information Seeking

A lack of detoxification support in the region was described by family participants as stimulating home detoxification decision making and information seeking.

No one knows where to go or who to contact, that's what it is, it's all home detox now. There is nowhere.' Family Participant 10

What information? There is no information around at all, you hear people saying I detoxed my son, I detoxed my husband, I gave him DF118's for 4 or 5 days, I supervised them, I locked them in their room, that's putting them through torture, that is not a detox,' Family Participant 9

'There is nothing or nowhere to go if your child is on drugs, there is nowhere to detox, only at home and it's a horrible thing to have to do, but it's the parents only option, it's their only choice. Family Participant 4

General practitioner supports and information provision for detoxification were described as lacking. Several family participants described learning about detoxification processes from personal and peer experiences in their communities, and used the internet to find information around home detoxification.

I learnt from stopping the first feller suddenly to bring the second feller down gradually, which I managed to do, but the first feller went cold turkey. The shocker was the other feller, who was on heroin, that I had no idea, I was so wrapped up in trying to keep my own head together, trying to keep the other two boys together that I didn't realise he was addicted to heroin. So I went and got information on home detox for him, I got information on the internet, it wasn't

great information, but it kinda helped because the doctor this time was able to give me medication, by doing it the right way by giving them to him when he needed them, I was able to bring him down so he is 18 months clean.' Family Participant 4

My thing was asking the doctor, but she did not want to know or she did not know herself. What do I do? They say talk to your doctor, so you talk to your doctor and there is no information there either, I did not get any support or help,, the most support I got were from women who had been through it with their own kids, and that was emotional support. I felt in my own wilderness, it was very scary, you just get on with it and do the best you can.' Family Participant 2

Urine Screening, Treatment Uptake and Self Detoxification

Several family and individual participants described how attempts at self detoxification occurred in efforts to access residential treatment, where '*clean urine*' screening was an entry requirement.

'So we bought him to XXXX [treatment centre] and he gave a dirty sample, so they told him sorry, no you cannot stay here, we had to go home. Family Participant 5

I remember going to a treatment centre a year before, and told me I had to give a clear urine, my thinking at the time was if I could give you a clean urine I wouldn't be here. Now I know the difference between being able to give a clean urine and being well, but at the time I couldn't get my head around that asking for a clean urine, it just wouldn't have been possible. 'The only reason I stopped was to go into the treatment centre, it was the only way of getting in there, was to give a clean urine, I failed and I could not give a clean urine, but I was at the stage that the doctor felt that if I didn't get in, I was a threat to myself, so I was lucky to get in on that, but detox was not mentioned, it was about giving the clean urine, it wasn't even about the process about detoxing the body, to allow me to work on myself, to start which I believe detox is, it's the first step in recovery, take away the substances and after a small period, you can start working on the under lying issues that are driving it.' Individual Participant 1

The inability to access formal addiction treatment whilst still using was described as contributing to suicide ideation and risk. In some instances, treatment centers accepted individuals at risk of suicide completion without the required '*clean urine*' screening.

'At one time he tried to commit suicide with an overdose. He has tried to commit suicide about four times in his life time due to the drugs. I do call them [Treatment Centres] all the time and

since then he has tried to commit suicide twice He is now asking for the help, he has now asked us to help him.' Family Participant 5

Financial Barriers, Treatment Uptake and Self Detoxification

Financial barriers to accessing formal addiction treatment included costly assessment procedures, lack of funded places and the presence of long waiting lists for funded treatment were described as impacting negatively on uptake of formal treatment pathways and contributing to attempts at self detoxification within the home setting. Some parents described taking out large Credit Union loans in order to pay for their child's treatment (amounts of up to \pounds 16,000 were mentioned) and lengthy journeys to treatment centres.

That's another big thing is the money. People cannot just afford it, there is information out there, but there is no information on the funding. If you want to go down and talk to these people, it's a $\in 80$ assessment fee, where in the hell is someone going to get $\in 80$, if they are living on $\in 150.00$ a week straight away, it's a barrier. They have to organise transport, you're talking about a day down, you need money for food, you need money for petrol, you need your $\in 80$, you need about $\in 200$ in reality. I know a lady who was 76 yrs. of age, she had to travel the whole way down to the treatment centre, she had no transport, so she had to hire a lad to drive her down, she had to go up and down several times and they didn't take her grandson. They charged her $\in 80$ for the assessment and then $\in 20$ after that again, she left herself with no money for that week at 76 years of age.' Family Participant 2

"They still sat us down and gave us an assessment which costs us $\epsilon 60$, it cost my grandmother $\epsilon 60$, she didn't really have that money and he [Uncle] didn't have it either, we don't have financial means to bring him to a special unit." Family Participant 5

Self Detoxification Experiences

Several individual participants described unpleasant detoxification experiences which included cold sweats, shaking, insomnia, paranoia, diarrhea and nausea often lasting longer than several days.

There were a lot of sweats and sleeping, it took me a while, it was hairy for a number of weeks. It took me a while to start sleeping and eating again, there was paranoia and there was anxiety, agitation and feel and loneliness and all this stuff? Individual Participant 8

A lack of understanding of drug addiction, physical and psychological dependency and the potential risks of self detoxification were described by most family participants, and was observed to impact negatively on the care they provided to detoxifying family members.

Looking back, I didn't fully understand the whole thing and how strong the drugs are on the way, it affects the brain. I was thinking if they could stop taking the drugs and get them out of their system, it will be ok. I did not realise what drugs did to you. I was more aware of it with my son, I was terrified my son would overdose, even looking back on it, the craziness of it going in and checking to see if my son was alive.' Family Participant 2

Now I know it's probably one of the most dangerous things you can do for yourself and the addict because when he gets seizures, when he detoxed from heroin, he didn't get any seizures just really bad shakes, screams, climbing the walls and aching whereas with the tablets, he gets the seizures that he needs oxygen, if that had happened when he was doing a detox, I would have woken him up and he could have gone back to sleep and died, if he had gone into a coma.' Family Participant 5

The need for specific family support in the form of medical and psycho-social assistance for those seeking to detoxify alone was described by many family participants.

He more or less did his detox at home alone. You're in between the doctor and the family member that is going through pain and agony, he did it a few times go cold turkey, then he would go back on it again. He needed something that I could not give him. He needed a whole lot of support and help from every avenue possible, he needed to talk to people that had been through it and gone through it. They need all round professional help, the family needs to know exactly what is going on, what's happening to this person, that this is normal for a person that is coming down or detoxing this is normal behaviour of someone there, their mind is messed up because it's not getting the drugs, that would help a family an awful lot.' Family Participant 2

Some individual participants also described unpleasant experiences of detoxification, the lack of information around safe detoxification processes, the length of time needed to fully detoxify and reflected on the potential for harm in unsupervised attempts to detoxify without close medical supervision.

I detoxed, didn't work at any level, it was more harmful than anything.' Individual Participant 2

The problem is getting clean for three days. I was thinking if I could get clean for three days, I would be alright, those three days are the most frightening of any addicts life, this is where you need the help, they can't give you that help, they can only give you that help after that, I fought for my life and that the way I look at it, I won't be giving it up so easily again. I am a Mummy again, it's all worth it, because I thought I was dead.' Individual Participant 5

Some individual participants questioned whether home detoxification was feasible and appropriate given the nature of addicts, and highlighted the need for professional advice and supervision.

I detoxed myself without any medication. I stayed at home my eye balls turned yellow. I fell apart and couldn't sleep for weeks. The nightmares were the worst when you're awake and not asleep, that's the worst part and the shivers and cold sweats going through a detox is really bad, the aches and pains...it was that bad, I nearly gave in and had a smoke of the gear. Going through detox is the hardest thing you go through in your life, but you have to go through it without taking a drug. You understand then what heroin really does to you, because most people who go through detox do it with medication, take Xanax, its putting you half asleep and you're not feeling the detox and then after three or four days, they think they are grand then they go back smoking the gear. The detox lasted for weeks, not days getting the stuff out of my system, your appetite is gone, you're physically drained, all I was doing was drinking water and milk, you cannot lie still, you're twitching all the time.' Individual Participant 6 I am sure there is a safe home detox, but I am not sure of what they are, that can be administered, that home detox is an option for some people, that information isn't really out there, if it is, I don't see it as accessible. I think its badly needed, if someone does not detox properly they can die, that is the bottom line, I think that information should be out there, first of all, that detoxing at home, self medicating all that type of stuff without supervision can kill you. I think that it needs to be out there, if there is a safe home detox that can be self administered by the doctor to a family member on a daily basis. I have friends that tried to detox from heroin, but were given 30 DF's in one go, an addict is going to use them and even if they are given to a family member who sees that person going through severe withdrawals, a person withdrawing like that can be very manipulative, can be very cunning, very convincing, it's really the job for a professional I believe." Individual Participant 1

Detoxification and the Family Bond

All family participants described the closeness of the parent and child bond in helping them to support their child's detoxification at home.

I would go through it again with one of them if I had to. I would rather have a place where my son could detox, rather than watching them go through it, even to watch the youngest feller come off the heroin was the hardest, I have never seen anything like it in my life.' Family Participant 4

What worked for my daughter being there for her, rubbing her head, telling her it was going to be ok, all of these things, not to be on her own, it worked for her but it worked against her in another way, I suppose that she felt so bad that her mum had to do this.' Family Participant 2

What worked was the sheer love I had for them to be honest, it was my passion, I wasn't going to let them down the road that I was after coming down.' Family Participant 6

The need for support from family members for those undertaking home detoxification was also underscored by some individual participants.

My sister gave me a lot of support and made sure I went to the doctor and the treatment centre, like most addictions you're ready to go, but when you're ready to go, you feel like backing out. Having the support of my sister helped, I probably would not have been able to do it without her, it is a hard thing to do and you do need support.' Individual Participant 1

Individual participants who were homeless at the time of detoxification described how hostel staff became like family members in providing support during the process.

The staff in the hostel are my family...helped me 100 %, they were coming up checking me every couple of hours, do I need water, do I need anything, they will always help you.' Individual participant 2

However, several individual participants described home and street detoxing alone and hiding their detoxification from family members.

I did it myself, I didn't want any help.' Individual Participant 6 Other individual participants described how the close family bond supported them during both hidden and family supported detoxification attempts and encouraged them to endure.

Its only now my trust is being built up with my mother and the family, it's a great step for me, it encourages me to detox and get off. I know it's not going to be easy, but I am going to have to do it, it's as simple as that. I tried to detox at home but couldn't do it, I tried to detox without my mother knowing, but it did not work, so I had to break the news to her.' Individual Participant 3

Detoxification Impact on the Family

Many family members had personal experiences of detoxification, but described how supporting their children detoxify in home as extremely upsetting, which in some instances involving locking their children into rooms, neglect of other family members (usually children) and how this all consuming process impacted on the family as a whole. The impact on the family was described as devastating, and causing intense and long term suffering for family participants. The detoxification process was described as exhausting and in some cases unsuccessful.

I have detoxed myself at home from alcohol and cocaine addiction, so when I got clean, my role was centered around fixing them, get them off the drugs, get them clean, I have also detoxed two sons from benzo's and one from heroin at home. It was horrible for myself, it wasn't too bad, as I was feeling the pain when my kids were feeling it, it was worse, it's harder to watch your own children going through it, without having nowhere to turn to.' Family Participant 4

We detoxed my brother at my sister's house, because we couldn't bring it on the parents, we were all there and we all went through different stages with him, it was a nightmare from start to finish, we had him in a room for five days, trying to jump out of windows, he wanted medication, he wanted all the pain to go away, he was in so much pain, it was hard as a family, we were all bought into it and we all had to do our own bit.' Family Participant 10 'It's been lousy, it's horrible, my first experience was with my daughter, she was on heroin and a lot of prescribed medication, she suffered from depression as well, like all mother and parents I have to get her off this. My whole interest was getting my daughter better getting her detoxed , getting her into rehab, getting her off drugs and live happily ever after, so I was totally focused on this with my daughter. I had heard about it, but it still didn't prepare you for coping with it yourself, the cramps, the crying, the pain, the hallucinations, the sickness trying to get her and to see sometimes it's like a evilness that you see your child, it's horrible, my kids were watching this, as well I tried to protect them as much as I could. I thought I was doing a wonderful job, I was so focused on my daughter, I lost vision of what was happening in the house. They were all

there, they were all going through it, they were watching it. I was oblivious to what was going on for them they were having a horrible time. I didn't even see it. If you asked me would I do it again the answer would be no. I would never put my family or myself through that again because it doesn't work.' Family Participant 2

Many family members described instances of aggressive and hostile behaviour in addicted children as impacting negatively on them and their families.

I tried to do a home detox in our family home, we did it for four days and he got to the stage, where I was giving him his dinner and he attacked me inside, I know he didn't want to kill me, he just wanted to get out of the room.' Family Participant 5

Detoxing at home..he cannot do it, he keeps being drawn back to alcohol, as alcohol is his addiction, when he didn't have it, he would be very aggressive, would lie through his teeth and he would break up my house to get what he wanted to keep his habit going, and that's the way I would have experienced it and it didn't work. He was just too aggressive and it was easier to let go and not confront him and let him do what he wanted to do. 'Family Participant 6 'You think they might be asleep and doze off and after five or ten minutes, they are up, they are walking the walls, they get violent as well, they do get violent. I had to run out of the room to get away from one of them, because I would say the state they were in they would have killed me, trying to get the drug. I persevered because I wasn't going to let it happen. I wasn't going to lose them. I would never ever give up on any of them.' Family Participant 4

Family members supporting and taking care of those detoxifying described the long term mental health and family functioning implications, and underscored the need for long term support mechanisms. Family support services was emphasised as an essential service in the region.

It has devastated the family, but we are very close, but we all suffer in our own way, its constantly something, we have had enough.' Family Participant 1

Lately it's like we have just had enough, we have another son and its affected him quite badly we are a mess, its chaotic that's the only word I can use. Family Participant 3

Terrible. I had a daughter she was living at home at the time and she was pregnant, he pulled a knife on her twice so she left home. I had a nine year old who would constantly run to his room close the door or run to a neighbors, he was terrified of him, I am terrified of him, our relationship went to breaking point. The only way I could see a way out of it was to commit suicide, so I tried that twice, but it didn't work so I got help myself in the end, he pushed us all to the very limit. Family Participant 6

It had a big impact there were a lot of resentments. I had it in my head I could fix her. I don't think I could face doing another detox at home; it took too much out of me. It ripped us all apart and we are still mending fences after the last time and that was two years ago. I have been thinking about doing another home detox with my eldest daughter, but with having a child in care, I would have to still be there because the social workers wouldn't allow it at home.' Family Participant 7

It has completely spilt the family. I have not spoken to one of my sons for over a year. I don't know if the division will ever be sorted out, it has left so many scars.' Family Participant 8

Relapses and Aftercare Supports

Instances of relapse were described as frequent by both family and individual participants, who emphasised the need for timely residential treatment uptake, post detoxification in the home, the need for a safety net of support and stabilisation systems for those self detoxifying in the home, and on discharge from residential treatment facilities. Aftercare provision appeared confined to AA structures in the community. Many family participants described the cost of aftercare as prohibitive and impacting negatively on sustained abstinence post detoxification and treatment.

'He came out of XXXX [Treatment Centre] and it was back to square one again. I know a lot of people offered to help and said yeah they would be there, but there was nobody there at the end.' Family Participant 6

'She did well in rehab and she was supposed to go onto secondary care, but there was a waiting list of two months, so she had to come home. Sure she was here a week and back at square one, so you're going through the whole process again. I really thought it was going to work. It didn't work and all the emotional turmoil, the hard work, you get no sleep, you're alert for everything ,you're terrified, you're terrified, they are going to run out of the door'. Family Participant 2

It was heartbreaking. You would often wish they were dead because you know it won't last without a proper detox and a follow up program.' Family Participant 9

Individual participants observed difficulties in undertaking methadone maintenance treatment and attending aftercare whilst on methadone.

When I get off the methadone, that's when I will start going to aftercare. Its pointless going to aftercare on methadone, I feel like methadone is still a drug, why go to aftercare when you're on methadone. You're still on drugs. I take everyday as it comes, you never know when you're going to break, all it takes is for one thing to trigger it off.' Individual Participant 3

Recommendations for Community detoxification service provision

Family and individual participants described the need for improved regional and local medical and psycho-social detoxification supports in the Mid West, alongside the need for improved information for families and individuals seeking to detoxify provision of needle exchange and harm reduction services, and increased regional treatment and rehabilitation provision. Several family participants described the need for a safe place for individuals to detoxify in the community.

We have not got any community detox in the first place, so I would like to have one. I would love to see a whole interagency approach around the area of addiction and drug misuse. Everybody working together from the time that you discover a family member has a problem, that you can go to some place and get your information that it can be followed through what your options are and to talk to people who have been through it. 'Family Participant 2

I think there should be a lot more help. I think there should be people that are experienced that they know what they are doing, they know what you're talking about to help them cope, to get through it and to be there for them afterwards. There needs to be a place to go to talk, if they get the urge. There needs to be someone at the end of the phone. There needs to be more help in the communities. I know a few kids that have overdosed and maybe if they had the support they might be still alive.' Family Participant 6

'A place, be it a house, a centre, a room, a shed....a safe environment where the person, the addict would become detoxed from whatever drugs they are on.' Family Participant 5

Individual participants who has detoxified in homeless accommodation also described the need for a safe place to detoxify, which in some instances was observed to be better placed away from the family home.

I really think that detox should be done in a safe environment with medical supervision. When I was in addiction I did not feel a part of anything, I didn't feel part of the family, totally disengaged from them, I was not in a place to accept help. It would have been more disruptive if I had been at home with my family back then. 'Individual Participant 1

Chapter 4. Discussion of Findings

The research yielded an illustrative phenomenological 'snapshot' of individual and family perspectives on self detoxification. In depth interviewing was conducted in order to uncover context specific subjective experiences and personal perspectives (Dale, 1995; Fountain and Griffiths, 1999 Neale et al., 2005). The findings are largely supportive of earlier studies on self detoxification, where self detoxification is conceptualized as an active process for the drug user (Gossop et al., 1991; Noble et al., 2002; Ison et al., 2006; McDonnell and Van Hout, 2010; 2011). A variety of definitions of detoxification were described, which centred on the management of drug induced withdrawals, and the achievement of abstinence. However, several family participants also described self detoxification as pre cursor to treatment uptake and opportunity for drug and alcohol rehabilitation. Similar to other research, life turning points were described by participants as stimulating decision making around self detoxification, and which included the loss of important family relationships, overdoses, incarceration, death of drug using friends, and reaching crisis points. Such turning points in the life course of drug use and addiction has been reiterated in previous Irish research undertaken in the South Eastern region (Van Hout and McDonnell, 2010; 2011). Similar to research by De Maeyer et al., (2011), the relinquishing of previous addictive patterns, lifestyles and user networks was described as contributing to successful detoxification and community rehabilitation.

Of note is that self detoxification was reported from a variety of inter changeably used substances (alcohol, heroin, cannabis, cocaine, methadone, codeine based products and prescribed medication), with poly drug taking, drug displacement patterns and self medicating attempts described during detoxification. Of concern is the lack of general practitioner advice and supports during home detoxification, and in particular relating to prescribing of anti anxiety medication. There is a need for improved information provision from prescribing general practitioners around the safe use and tapering of support medications for those undertaking a home detoxification. Unsupported family members reported the purchase of licit and illicit street drugs (alcohol, street sold prescribed medication, cannabis) to medicate their family members' so as to help ease withdrawal symptoms during detoxification. This was observed to contribute to occurrence of mental and physical health issues such as psychosis, suicidal ideation, '*benzo fits*', aggression, paranoia

and the development of new drug dependencies. These issues were observed to impact negatively on treatment uptake in the case of prescribed medication dependence. In some instances, the potential of user harm in the form of suicidal ideation opened the door for treatment uptake. Mixed views were observed with regard to methadone maintenance treatment and its relationship with self detoxification. Similar to other research, methadone was observed to be more difficult to withdraw from than heroin (Winstock *et al.*, in 2011; Van Hout and Bingham, 2011) and in this research appeared to facilitate self detoxification decision making and attempts. Awareness of the benefits of methadone maintenance treatment appeared low. Indeed, critiques of methadone maintenance remain centralised in its status as substitution treatment and contradicting with abstinence focused treatment ideals (Joseph *et al.*, 2000; Bell *et al.*, 2002; Vigilant, 2004).

Some family participants described the stigma of child, spousal and personal addiction, and prejudicial experiences when attempting to access services. Public attitudes to heroin use in particular reflect 'a negative view of drug addicts' (Luty and Grewal, 2002:94) and with stigma blanketing family members (Corrigan and Shapiro, 2006). Indeed, research has described private, public and institutional forms of stigma relating to drug addiction (Bell et al., 2002; Vigilant, 2004; Ormston et al., 2010) and tensions between health professionals, potential clients and their families (De Leon, 2000; Butler, 2002; Foster et al., 2005; Patterson et al., 2008; Van Hout and Bingham, 2011). In response to experience of negative service encounters, and costly experiences when attempting accessing services and secure funded treatment places, family participants accessed information around home detoxification from personal, sibling and peer experiences, and also used the internet to find information around home detoxification. Family participants appeared responsible for both seeking information on detoxification and treatment pathways, and funding of treatment. A lack of detoxification information was observed in local general practitioner surgeries. In addition, the requirement for a 'clean' urine screening was described as contributing to home detoxification decision making. The role of service providers and the consideration of individual user wishes are paramount in treatment care planning, as such perspectives influence, mediate and inhibit detoxification success, treatment entry, retention and rehabilitative outcomes (Horvath & Symonds, 1991; Broome et al, 1996; Nelson-Zlupko et *al.*, 1996; Broome et al, 1997; Joe et al, 2001; Kasarabada *et al.*, 2002; Noble *et al.*, 2002; Shen et al, 2002; Siqueland *et al.*, 2004; Bobrova *et al.*, 2007).

A variety of unpleasant detoxification experiences were described by individual and family participants which included cold sweats, shaking, insomnia, paranoia, diarrhea, nausea, aggression and seizures. Family participants described a need for improved information around drug dependency and the risks of detoxification from health professionals and drug Of interest is that some family participants had undertaken detoxification services. themselves, or reported assisting several children in their home detoxification. This personal information was used to assist individuals when detoxifying. Several individuals questioned whether home detoxification was indeed feasible and safe, when considering the potential for harm and addictive behaviours, and the need for professional involvement in the process. Despite this, families are increasingly recognised as agents for therapeutic change and play a significant role in the success of substance misuse treatment (Barber, 1996, Meyers et al., 2002, O Farrell and Fals-Stewart, 2006; Copello et al., 2009). According to Copello and Orford (2002) addiction models which incorporate the family support system contribute to a wider and more lateral understanding of addiction. All family participants described the closeness of the parent and child bond in helping them to support their child's detoxification at home, despite frequent reports of aggressive behaviour in the home and relapse cycles. The literature underscores the problematic nature of opiate dependence in particular (Van den Brink et al., 2003; Van den Brink and Haasen, 2006, Schuckit, 2006; Raby et al., 2008; De Maeyer et al., 2011). The impact of home detoxification experiences, particularly in the case of opiate dependence were described as devastating, and highlighted the long term need for family support systems. Family support services was emphasised as an essential service in the region. In particular, the psycho social support of families when in the process of detoxification is much needed, alongside the piloting of dedicated Community Detoxification Teams consisting a Co-ordinator, Drugs Worker, Nurse and General Practitioner and operating within an integrated care pathway. The findings also highlight the need for improved levels of formal treatment places and aftercare service provision in the community for individuals post detoxification.

Chapter 5. Key Recommendations

The following are a series of key recommendations arising from the research findings.

Information Provision

- 1. To highlight the National Drugs Help Line;
- 2. To produce web based and health service information that can sign post individuals seeking assistance to drug and community based services in the Mid West;
- To ensure visibility of the National Community Detox information leaflet in the Mid West;
- To advise services and families of the <u>www.drugs.ie</u> website which provides information on community detoxification and distribute the DVD;
- 5. To have Community Detoxification and Prescribed medication awareness workshops for drug users and their families (i.e during local drug awareness events);
- 6. To provide additional training courses with support from the PRI and the ICGP regarding awareness raising of home detoxification, the need for improved information provision and health professional involvement.

Community and Family Support

7. To develop a support group that has had experience of self and family home detoxification in conjunction with the family support services in the region and the MWRDTF.

Services

- 8. To have a low threshold drop in service to provide referral pathways to community detoxification, treatment, step down, aftercare and rehabilitation services;
- To provide community detoxification within existing service provisions in the Mid West, and as described by national community detoxification protocols;

- 10. To provide a community based stabilization programme in an existing project(s);
- 11. To provide additional training on community detoxification protocols for existing staff and in conjunction with PRI;
- 12. To have adequate residential detoxification accommodation in the Mid West.

Appendices



24th January 2012

A Chara,

The Mid West Regional Drugs Task Force is undertaking a piece of research in conjunction with Waterford Institute of Technology in relation to family experiences of home or self detoxification from alcohol and/or drugs.

There is very little qualitative information on home and self detoxification experiences of the person and the family and it is intended that this research will help inform the development of improved community detoxification services in the Mid West region.

At this point we would like to make you and your agency aware of this research study and we would also like you to promote it and encourage people you know who have experience of detoxification or where there is an experience of home detoxification in the family, to participate in the study.

The field research (participant interviews) is planned for March 2012. As with good practice in research, identities of participants will remain anonymous. Interviews are expected to be 40 minutes and will be held in a neutral venue (a place where the participant is comfortable and safe).

We appreciate any support you can give in promoting this research with possible participants. If you would like further information on the research, please contact the MWRDTF Development Worker, Rionach Power (ph 086 0433510) or <u>rpower@mwrdtf.ie</u>. Or alternatively contact Tim Bingham 086 389 3530 email info@timbingham.ie

Kind regards

Gearoid Prendergast Co-ordinator

> Unit 5 Steamboat Quay, Dock Rd., Limerick Tel: 061 445392 Web www.mwrdtf.ie



Participant Consent Form

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Study title: A qualitative study of family experiences of home or self detoxification from				
alcohol and/or drugs.				
I have read and understood the Information Leaflet about this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.	Yes 🗆	No 🗆		
I understand that I don't have to take part in this study and that I can opt out at any time.	Yes 🗆	No 🗆		
I am aware of the potential risks of this research study.	Yes 🗆	No 🗆		
I have been given a copy of the Information Leaflet and this completed consent form for my records.	Yes 🗆	No 🗆		

Participant Name (Block Capitals)	Participant Signature	Date

.....

To be completed by the Principal Investigator or nominee.

I, the undersigned, have taken the time to fully explain to the above individual the nature and purpose of this study in a way that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.

Name (Block Capitals)	Qualifications	Signature
MARIE CLAIRE VAN HOU	T P.hD, M.Sc.	
	Date	



Waterford Institute of Technology

Information Leaflet

You are invited to participate in a study entitled 'A qualitative study of family experiences of home or self detoxification from alcohol and/or drugs' that seeks to learn more about your experiences of a family member detoxing from alcohol or drugs in the home. We have received ethical approval for this study from the Health Service Executive in the South East of Ireland. The findings will be used to inform the development of improved community detoxification services in your area. I (Marie Claire Van Hout) am the researcher and I will be interviewing people for this study.

The interview will last about 1 hour. I am <u>not</u> collecting names or other personal identifiers – people's identities will remain anonymous. Your participation in this study is voluntary. You can withdraw from the interview at any time. If any criminal activity is disclosed during the course of the interviews, I will encourage you to report this.

I ask for your consent for me to tape the interview. If you are uncomfortable with having the interview taped, you can say so and I will take notes during the interview. If names appear in the tape, I will omit this information shortly after the interview. I will transcribe the tapes shortly after an interview is completed and I (Marie Claire Van Hout) am the only person who will have access to the tapes which will be in a locked cabinet. The tapes will be destroyed post transcription. The transcribed narratives will be stored on a password protected computer at Waterford Institute of Technology.

Should you become distressed as a consequence of partaking in the research, I will provide you with contact details of your local Family Support Services worker. Thank you.

Dr Marie Claire Van Hout

Interview Guide

- What do you understand when I say 'detoxification'?
- Can you tell me, in as much as you feel comfortable in sharing with me right now, what your experience has been with regard to a family member's detoxification in the home setting?
- Can you explain to me their reasons for seeking and attempting detoxification at home?
- What were the primary and secondary problematic substances?
- Who helped this family member detoxify?
- Did community and medical detoxification supports meet their needs and expectations?
- How did you support this family member through withdrawal?
- Where have you gotten information on home or assisted detoxification from?
- Were you aware of any dangers of home detoxification?
- What was helpful? Not helpful?
- In hindsight, would you do anything differently now to support home or community detoxification?
- What would you change within home or community detoxification service provision in your area at the moment?

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