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Impact of Drug & Alcohol Related Deaths on Families – March 2018

Dr Sharon Lambert, Applied Psychology, University College Cork
in collaboration with
The National Family Support Network



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Acknowledgements:

The National Family Support Network for pushing the agenda of families impacted by substance related bereavement.

Thanks are due to the College of Arts, Celtic Studies and Social Sciences (CACSSS), University College Cork for proving funding for travel, this facilitated the researcher to conduct interviews in families own homes. To the psychology interns Ian, Akville, Eloise & Sibeal for the assistance with transcribing.

Most importantly, there is huge gratitude due to the family members who allowed the researcher into their homes, for their honesty, for the welcome, for the tea and cakes, for the tears, for the laughter and for the wisdom. This would not have possible without you. I hope the report does justice to your voices and to those whom you have lost. This report is also dedicated in memory of Mary, a mother who participated in the study.

Grief is the last act of love that we have to give those that we loved.

Where there is deep grief, there was great love.

The Author

Dr Sharon Lambert joined the teaching staff in the School of Applied Psychology in 2014 following a number of years working within community settings. Sharon's research interests revolve primarily around the impact of trauma on development, its link with substance misuse and mental health and consequent considerations for service design and delivery. Sharon regularly delivers training to professionals working in front line services and presents at conferences nationally and internationally. She is published in the areas of substance misuse, complicated grief and homelessness.

Foreword

Supporting families affected by bereavement through substance misuse has been at the core of the National Family Support Network's work since the organisation began in the year 2000. An organisation which was established by family members in response to the epidemic of drug related deaths in inner city Dublin and the lack of state response. In partnership with Citywide Drugs' Crisis Campaign, the National Family Support Network held the first service of 'Commemoration and Hope' in 2000 and this service has been held annually on February 1st every year since. This service provides families affected by a death through substance misuse with space to grieve for their loved ones in a spirit of dignity and hope, an opportunity commonly stolen from families affected by substance misuse as a result of stigma.

The National Family Support Network recognised from the beginning that a key element needed to support families who had lost a loved one through substance misuse was to identify, acknowledge and record these deaths as drug-related on a national index. As representatives of family members affected by substance misuse, we campaigned for this mechanism to be put in place and the National Drug's Related Death Index was established in 2005 as an action of the 2001-2008 National Drug's Strategy and this has been a key resource in advancing government policy on substance misuse.

Despite the importance of this data however and despite being able to identify how and when our loved ones were dying, we were unable to explore the affect this has on family members, which is why we were so thrilled to partner with Dr Lambert on this project. This research explores and confirms what we have been hearing from families for years, highlighting; the difficulties families face navigating addiction/mental health services, financial and drug related debt issues, stigma and difficultly in grieving and the impact of family support services on helping to heal families torn apart by grief. This research gives a voice to those families who have been historically neglected by services, who are stigmatised due to the role substance use played in the death, shamed, in many instances, for being a parent of a person who uses drugs or for not acquiring life assurance for their loved one when in reality people in addiction cannot be insured in this way, therefore leaving families in significant financial strain after a death which may include drug related debt the person has left behind. Perhaps most essentially, this research illustrates the key message which we in the National Family Support Network have known all along, that family support and addiction specific bereavement supports make an essential difference to families no matter where they live, their composition or the unique circumstance of their journey.

The findings and recommendations of this research seek to strengthen action *2.1.17 A* in the current National Drugs' Strategy 'Reducing Harm, Supporting Recovery 2017-2025' which identifies the need to develop addiction specific bereavement supports for families, an action which the National Family Support Network successfully proposed during the strategy's' development. We know from working with families over the years and now again highlighted within this report, that generic bereavement services often don't work for families affected by substance misuse, instead they compound feelings

of shame, stigma and unresolved complex grief. This experience emphasises Dr Lambert's assertation that death through substance misuse should be treated as a 'Special Death' in the way that for example death through suicide is. A death which, due to complex circumstances can result in complicated/disenfranchised grief for the family and which needs the support of additional, specific, services. Essential too, we know that supports for families affected by substance misuse which will allow them to access timely and appropriate supports for their loved ones are key; including access to dual diagnosis services as outlined within this report, early intervention for children living in a family affected by substance misuse and access to training in Naloxone, something the National Family Support Network have been passionately facilitating for over a decade.

The National Family Support Network would like to express our immense and sincere gratitude to Dr Sharon Lambert who undertook this highly important, sensitive and transformative research. As a small, civil society charity, our organisation has little access to resources outside of core staff and overhead costs, so the opportunity to partner with such an esteemed and passionate academic without additional resources, was an exceptionally rare but fantastic experience.

Finally, we would like to give our deepest gratitude, support and solidarity to the generous, open and brave families who agreed to take part in this project, we will ensure that your contributions will have a significant impact on the way in which families in Ireland experience death through substance misuse, through our onward advocacy, policy and development work.

To all of the families who we have not met yet, support is out there, you are not alone, please contact the National Family Support Network today and reach out.

Sadie Grace

CEO National Family Support Network

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Executive Summary

- **Background and Aims**

The Health Research Board in Ireland reported that during 2015, there were almost two drug related deaths per day that is 695 individuals (HRB, 2017). The European Monitoring Centre for Drugs and Drug Addiction reported that drug induced mortality rates in Ireland are at the higher level of the scale (EMCDDA, 2017) and the European Drug Report (2017) places Ireland as the 4th highest mortality rate for Drug Related Deaths and well above the EU average. Substance misuse is one of the major social, legal and health burdens and it continues to grow both nationally and internationally (Schmitz, 2016). While there is some literature surrounding the impact of living with problematic substance misuse (Templeton, 2013) physical and mental health implications have been reported (Adfam, 2012), little is known about the experiences of 'the bereaved' who have lost a loved one to overdose or other drug or alcohol related complications. There are only currently five published studies globally on the impact of drug related deaths on the bereaved; it is argued that bereavement due to substance misuse is a 'special death'.

Special deaths are those where there is increased impact on the individual, the family and the society (Guy & Holloway, 2007) and have an increased likelihood of complicated grief and/or disenfranchised grief. Complicated grief is grief which prevents a person from accommodating their bereavement and which does not lessen over time (Worden, 2009; Tobin, Lambert & McCarthy, 2018). Kenneth Doka (1989) defines disenfranchised grief as grief and loss which is either not acknowledged, or is devalued because of characteristics of the death or of the bereaved. Research has also identified a prolonged grieving process by parents for the living child who is lost to drugs, and where a death occurs there is in effect a 'double death' (Oreo & Ozgul, 2007). Research has found that parents bereaved due to DRD's were significantly more impacted by grief and mental health problems than parents who lost children to accident or illness, with the impact comparable to parents who had lost a child to suicide (Feigelman, Jordan & Gorman, 2011). Yet we have failed to provide appropriate services to this bereaved group, nor do we systematically collect data on the number of individuals who are bereaved in this way.

The current study was initiated by the National Family Support Network in response to the lack of research on the impact of drug and alcohol related deaths on the family. Research is very limited with only a handful of studies globally (Templeton et al., 2016), and the current study is the first of its kind in Ireland, it is also the first study globally to interview multiple members of one family in the context of the family home.

The aim of the study is to explore the impact of substance misuse and related deaths on families in Ireland.

- **Methodology**

Seven families were recruited through the National Family Support Networks' main office in Dublin and individuals that expressed an interest in participation were sent an information pack outlining the nature of the study.

Seventeen bereaved family members were interviewed in the context of the family and these interviews covered the deaths of seven men and one woman. The relationships between the interviewee and those who had died included six mothers, three fathers, six siblings (1 brother & 5 sisters) and two nieces. The causes of death were 4 deaths by overdose and 3 by suicide (all by hanging). The age range of the deceased was 19-46 years old and all of those who died were white Irish, with an average age of 31 years. The time between the death and the interview ranged from one year to twenty seven years. There were 10 dependent children and 1 grandchild left behind.

Ethical approval was granted by the Ethics Committee in the School of Applied Psychology, University College Cork.

Interviews were transcribed and analysed using thematic analysis. The interviews were conducted in Dublin, Carlow and Cork and had an average duration of 93 minutes.

Two weeks post interview participants were sent a follow up survey containing 5 questions (see Appendix), which were largely qualitative in nature to ascertain their experiences of the research process. This information can be utilised to inform any future plans to replicate the study and to inform best practice in bereavement research by hearing the voices of the bereaved on the research process.

- **Findings**

The results highlight the adverse impact of addiction on families before and after the death of their loved one. The data generated four themes; living with use, experiences of services, discovering death and life after bereavement. The impact was felt financially, physically, psychologically and socially. All of the families interviewed detailed life before death; they described the chaos, heartaches and hardships associated with supporting a love one who was experiencing substance dependence. Families struggled to engage with organisations outside of the family in the early days as the shock and stigma of discovering their loved one's addiction prevented them from reaching out. For others, it appears that families were unsure about how to seek support and when they did seek help they were not always given the 'right help at the right time'. For those living with active use, this generated ill health, financial burdens and fractured relationships in the absence of clear support pathways. There was criticism of the lack of family involvement in adult services. It was argued that while services exist for those who are substance dependent, they are unable and 'too unwell' to access these services and that families should be facilitated more in guiding their loved ones collaboratively through the processes.

Families who are living with addiction have a range of services to navigate such as health, justice, education, social services and addiction support services. In some instances there were hugely positive experiences; however in others there were encounters with professionals that generated huge levels of stress and anxiety for families. Moreover, families reported that some of these experiences compounded what was already a very difficult situation. Stigma and shame was reported as a barrier

to accessing services and this shame appears to have contributed to at least two deaths by hanging in this study. Participants were hugely favourable to peer led groups and bereavement support groups specific to substance misuse, the positive impact that such groups had on the bereaved cannot be underestimated. Consequently families were very critical of the lack of funding provided to these grass roots organisations.

Life after bereavement revealed harrowing accounts of grief and trauma, and a clear sense of a neglected and overlooked pain. Family members in this study reported disenfranchised grief, where their loved ones' death is not acknowledged or is devalued. There is stigma and shame associated with addiction; people experiencing difficulties with substance dependence are marginalised and powerless.

The loss of a child is hugely traumatic for parents irrespective of how that death may have occurred;

> *"I would drive out to the grave, it was like I was making his bed, I would pat the whole thing down and fix it and everything"*

The whole family system is impacted and a continuing cycle of trauma is possible when the needs of the grieving go unmet. The children of those left behind are a particularly vulnerable group who require specialised community based bereavement support by organisations who understand the impact of substance misuse within the family.

- **Recommendations**

✓ Fund and provide specialised bereavement support programmes for the whole family, this may require an outreach support for those struggling to access services.

✓ Urgent investment required in early intervention for children living with substance misuse and appropriate supports for children bereaved in this way. The impact of these adverse experiences on child development should be addressed.

✓ Support and training for parents and care givers of children who are impacted by substance misuse. The impact of stress on child development should be communicated to caregivers and other adults in the child's life including professionals.

✓ Encourage services to utilise the National Rehabilitation Framework for inter-agency shared care planning. All relevant stakeholders (justice, health, mental health, education, addiction & social services) should engage.

✓ Dual Diagnosis appears to be a specialised service rather than a mainstream occurrence. There should be a clear national policy in relation to the roles and responsibilities of addiction service and mental health services management of people presenting with co-morbidity of mental health and addiction not a moral failing.

✓ A national media campaign is required to challenge the stigma surrounding addiction, where it is clear that substance misuse is a health issue.

✓ A robust training and awareness programme for front line services and professionals on the trauma and shame of addiction. The needs of substance misusers and their families should be communicated to all professionals likely to encounter this population.

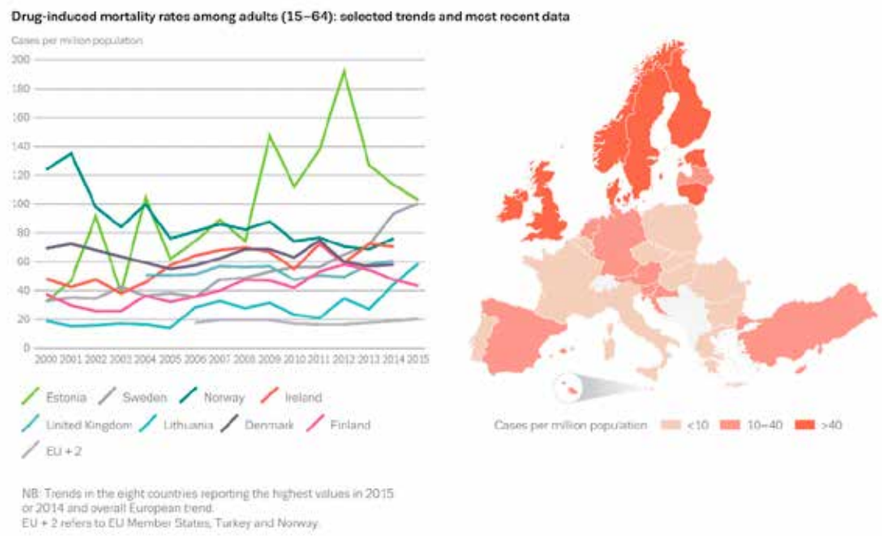
✓ Provide access to research funding to address the current gap in the literature.

1. Introduction

Substance misuse is one of the major social, legal and health burdens and it continues to grow both nationally and internationally (Schmitz, 2016). The UK estimates the associated costs at between £10-16 billion per year, and the U.S. has described addiction to prescription medication as at epidemic proportions (Nutt et al., 2010; Canon et al., 2014). In Ireland the Health Research Board reports that the number of drug related deaths (DRD's) increased 62% in the year period 2004 to 2014 (HRB, 2015). The European Monitoring Centre for Drugs and Drug Addiction (see figure 1) reported that drug induced mortality rates in Ireland are at the higher level of the scale (EMCDDA, 2017) and the European Drug Report (2017) places Ireland as the 4th highest mortality rate for DRD's and well above the EU average.

The Health Research Board (HRB, 2017) reported that during 2015, there was almost two drug related deaths per day, that is 695 individuals. In the same time period 425 people died by suicide, 196 died in Road Traffic Accidents and influenza was reported to have killed 27. Yet the issue has gained little attention in practice, policy and research with most literature reporting descriptive data on those who have died and little on those who have been bereaved (Guy, 2004). Additionally it is recognised that DRD's are broader than posioning or overdose and that death as a result of substance related issues can come in many forms such as accidental, medical complications, suicide and violence. The number of drug related deaths and deaths among drug users is used by the EMCDDA as one of the key indicators to measure consequences of drug use. Many juristications have yet to establish a clear method of recording such data. However the National Drug Related Death Index in Ireland was established in 2005 and is a census of drug and alcohol related deaths in Ireland recording overdose and non-poisoning deaths that have occurred in an Irish context (HRB, 2017).

Figure 1: European Monitoring Centre for Drugs and Drug Addiction, 2017



The World Health Organisation has described substance misuse as a growing major disease burden and the trends indicate that associated mortality is increasing (Whiteford et al, 2013). While most countries record these deaths statistically, there is limited research and literature regarding the impact and lived experience of the families affected. The area of drug related death (DRD) has failed to generate interest amongst researchers in the social sciences with most reported studies emerging from other disciplines such as epidemiology, pharmacology and emergency medicine (Feigelman, Jordan & Gorman, 2011).

While there is some literature surrounding the impact of living with problematic substance misuse (Templeton, 2013) physical and mental health implications have been reported (Adfam, 2012), little is known about the experiences of 'the bereaved' who have lost a loved one to overdose or other drug related complications. There are currently only five published studies globally on the impact of drug related deaths on the bereaved, one from Brazil, one from the United States and three from the United Kingdom. Guy (2004) published one of the first studies on the issue by exploring four UK case studies where one relative of the deceased was interviewed. The main themes identified in Guy's case studies reveal the complicated nature of bereavement due to DRD's. Family members report that the image of the person who has died has been tarnished by their involvement with illicit substances and this can be a barrier to experiencing grief, as if they are not entitled to grieve because the person who has died is in some way blameworthy. He reports that pejorative language surrounding drugs and drug users can compound this. There is a processing of the time period before the death where family members think about how they managed and navigated the person's addiction and whether the actions of family members may have made things worse. Guy concludes that practitioners need to be aware that bereavement work with families bereaved in this way must be cognisant of the complicating variables that impact on the grief process.

Da Silva, Noto & Formiggoni (2007), identified 6 individuals in Brazil who had died by overdose and interviewed one associated family member. The study grouped respondents into those who were aware of the drug use and those who were not, the authors concluded that families who were unaware were left with feelings of guilt and anger and a sense of missed opportunity to intervene. While the families who were aware were reported to have been left with a sense of ambivalence as there was a 'veiled preparation' for the possibility of overdose, resulting in feelings of both pain and relief. The study concluded that the deaths were always sudden and traumatic and that families in these instances should be provided with psychological support.

Fiegelman et al., (2011) completed a comparative study of 571 parents in the United States who had been bereaved in a range of different ways; suicide, drug related deaths, natural causes and accident. They concluded that suicide and drug related deaths resulted in complicated grief processes but that stigmatisation and lack of compassion for parents bereaved by DRD's were greater than for those bereaved by suicide. Work by Grace in 2012, titled 'On track or off the rails', was a study of four British teens aged 14-16 who were parentally bereaved by alcohol related deaths. The small scale but significant study highlighted a need for greater understanding and compassion for children bereaved through substance misuse. The children experienced 'disruptive grief manifestations' and their behaviour was perceived as 'bad' rather than 'sad'.

A study conducted with just over one hundred adults in England and Scotland, revealed five themes; living with the possibility of death, official processes, stigma, grief and support. The authors also noted

that there was much diversity between individual experiences and concluded that responses to this bereaved group should be individualised, they acknowledge how this is a challenge in a climate of cutbacks where there is increasing emphasis on standardised practices (Templeton et al., 2016). Further analysis of the data indicated stigma can be mitigated by acts of compassion and kindness from professionals who encounter the bereaved (Walter et al., 2017).

Bereavement research reveals that death has been perceived as 'good' or 'bad' where a 'bad death' is one where the person who has died is in someone culpable for their passing such as in the case of suicide, AIDS and substance misuse (Valentine, Bauld, & Walter, 2016). The reaction to a 'bad death' is evident in the ways in which family and greater society support those who have been left behind.

It is argued that bereavement due to substance misuse is a 'special death'. Special deaths are those where there is increased impact on the individual, the family and society (Guy & Holloway, 2007) and have an increased likelihood of complicated grief and/or disenfranchised grief. Complicated grief is grief which prevents a person from accommodating their bereavement and which does not lessen over time (Worden, 2009; Tobin, Lambert & McCarthy, 2018). Kenneth Doka (1989) defines disenfranchised grief as grief and loss which is either not acknowledged, or is devalued because of characteristics of the death or of the bereaved

While research to date on the impact of substance related deaths on the bereaved is sparse, all have reported that complicated grief and disenfranchised grief emerged from the data and that DRD's should be classified as 'special deaths' similar to suicide, murder and the death of child (Guy, 2004; Templeton et al., 2016; DaSilva et al., 2007; Fiegelman et al., 2011). Guy and Holloway (2007) argue that the traumatic circumstances of the death, associated stigma and disenfranchised grief are the reasons why DRD's fall into the category 'special deaths'. Additionally, previous research has identified that DRD's often happen after a period of abstinence (Bird & Hutchinson, 2003; Gossop et al., 2002) and this can compound the sense of shock as families may have been experiencing a time of hope and optimism for their loved one (Guy, 2004). Moreover, research has also identified a prolonged grieving process by parents for the living child who is lost to drugs, and where a death occurs there is in effect a 'double death' (Oreo & Ozgul, 2007). Research has found that parents bereaved due to DRD's were significantly more impacted by grief and mental health problems than parents who lost children to accident or illness, with the impact comparable to parents who had lost a child to suicide (Feigelman, Jordan & Gorman, 2011). Yet we have failed to provide appropriate services to this bereaved group, nor do we systematically collect data on the number of individuals who are bereaved in this way.

The current study looks at the impact of drug and related deaths on the family. Seven families comprising of seventeen affected family members discussed the impact of the early deaths of seven men and one woman during interviews.

2. Methodology

Families were recruited through the National Family Support Networks' main office in Dublin and individuals that expressed an interest in participation were sent an information pack outlining the nature of the study.

For the purpose of this research Koerner and Fitzpatrick's (2004) transactional definition of the family was utilised, i.e. "groups of intimates through their behaviour generate a sense of family identity with emotional ties and an experience of a history" (p. 177). The recruitment leaflets indicated that participation would require a minimum of two family members, however one of the interviews consisted of just one mother. During initial contact with the researcher the interviewee explained her reason for wishing to participate was to highlight the impact on her family, her son's death was never discussed amongst her family and this story of silence was a story that should also be told.

Interviews were used in this instance as this method allows for collection of rich data of peoples' lived experiences of a topic that to date has remained largely under researched. One interview was conducted in Cork, two in Carlow and four in Dublin. All interviews except one took place in a family home; one interview was conducted in the office of the National Family Support Network in Dublin. Interview lengths were dictated by the participants, ranging from 1 hour and 11 minutes to 2 hours and 40 minutes, the average duration was 93 minutes.

Data was transcribed and analysed using thematic analysis (Braun & Clarke, 2006 Lambert & O Halloran, 2008). Four main themes emerged from the data; Living with active use, experiences of services, discovering death, life after bereavement.

Two weeks post interview participants were sent a follow up survey containing 5 questions (see Appendix), which were largely qualitative in nature to ascertain their experiences of the research process. This information can be utilised to inform any future plans to replicate the study and to inform best practice in bereavement research by hearing the voices of the bereaved on the research process.

Ethics

Ethical approval was sought and granted by the ethics committee in the School of Applied Psychology, University College Cork. The literature on conducting research with bereaved families makes a number of recommendations and the following were included in this study;

Interviews conducted by a person;

(a) Who has prior experience of working with families in an addiction service
(b) Who has a qualification in family therapy
(c) Previous experience of qualitative research.

The families were carefully selected by those who coordinate the various support groups. Participation was voluntary, and participants were free to withdraw at any stage. Should participants experience distress due to participation they will have the full support of their relevant network group.

Exclusion Criteria: Persons under 18 years of age**,** a person who has been bereaved within the last 12 months and persons with an active addiction or mental health issue.

Positive Ethics Statement

The School of Applied Psychology, University College Cork is committed to achieving excellence in research and scholarship. The pursuit of excellent research and the fulfilment of our responsibilities to participants in research, research users and the wider community require the maintenance of the highest standards of integrity and ethics. Research should not be conducted for research sake, every effort should be made to disseminate as widely as possible so that findings can influence beyond academia. This project will be disseminated to those who can effect change in social policy, service design and delivery.

Profile of Participants

This study covered the early deaths of seven men (two of whom were brothers) and one woman. Seventeen bereaved family members were interviewed during seven interviews. The bereaved included four males and twelve females. The relationships between the interviewee and those who had died included six mothers, three fathers, six siblings (1 brother 5 sisters) and two nieces. The causes of death were 4 deaths by overdose and 3 by suicide (all by hanging). The age range of the deceased was 19-46 years old and all of those who died were white Irish, with an average age of 31 years. The time between the death and the interview ranged from one year to twenty seven years. There were 10 dependent children and 1 grandchild left behind.

3. Results

Four themes emerged from the interviews and they encompass lived experiences of before death, discovering death, and after death and all themes feature the impact of substance misuse on the family at each stage. The themes are; living with active use, experience of services, discovering death and life after bereavement. Each of the identified themes contain sub themes (see Table 1).

Table 1: Interview Themes and Sub-Themes

Themes	***Living with active use***	***Experiences of services***	***Discovering death***	***Life after bereavement***
Subthemes	Discovering substance misuse	The Role of Support	Failure as a parent	Disenfranchised grief & the cycle of trauma
	Impact on person abusing substances	A health issue or a criminal justice issue	Peace in death	Stages of Grief
	Impact on Family	Navigating Services	Special Death	Pulling apart
				Healing through Activism

Living with Active Use

All of the families interviewed detailed life before death, they described the chaos, heartaches and hardships associated with supporting a love one who was experiencing substance dependence, these accounts can be categorised into three themes; discovering the substance misuse, watching the impact on the person who was substance dependent and the impact of use on the family.

<u>Discovering the substance misuse:</u>

There were a range of experiences described by families in relation to how they first discovered the substance dependence and how they managed this knowledge. For many the substance dependence was discovered as a result of their loved one disclosing the news directly.

> *"He said, 'Ma, how can I convince you I'm taking heroin'. Oh Jesus I knew he was serious then. Drove all around, drove up on paths where we knew all the drug dealers was, knock them down, ah, I just went (…) berserk."*

> *"She said 'I've something to tell ya', I said 'what?', I'm an alcoholic and I said eh 'you're not' and I really didn't think like, I said to myself no, oh no she's not ya know"*

For others, they only became aware of substance misuse issues when their loved ones found themselves in contact with the justice systems. Within families the disclosures were not always shared with all family members in an attempt to protect parents from the news and were often not shared outside of the family home for some time due to the fear of stigma and shame.

> *"as you can imagine we weren't aware of treatment centres or anything like that and it just completely got out of hand. In those years we tried to cover up a lot of it. We tried to build a wall around ourselves and isolate ourselves so that other people didn't know"*

> *"I tried to, [my wife] was struggling with depression too and you know I mean I tried to conceal it from her, I honestly didn't think he was going to die but I knew he was dabbling in drugs but I really didn't know how bad his addiction was you know"*

The reactions among family members varied from shock, anger, disbelief and grief. What was clear from all of the interviews was that families in the initial months and sometimes years, did not know how to get support for themselves or for their loved ones.

<u>Watching the impact on the person who was substance dependent</u>

The impact of substance dependence on loved ones spanned a range of domains, impacting all aspects of their lives; physical, social and psychological. Parents and siblings recounted the pain of watching the physical deterioration in their loved ones;

> *"we looked at our son and you know he ended up losing the power of his legs he ended up in a wheelchair he lost an arm, he had an accident, he was 4 months in hospital after that, he died an awful death from drink, from alcohol, now really and truly like that, he ended up homeless, the latter end of his life he was in a hostel"*

> *"he had a sore throat, his throat was that bad, that when he was trying to drink a sup of tea it was coming out his nose"*

> *"he was nearly 22 stone (…) And I seen him going from 22 stone to about 8 stone (…) like that (clicks fingers) and that's what the drugs were doing to him."*

Stigma and shame consumed drug users and this impacted heavily on their psychological states, with two families reporting that this shame directly contributed to the death by suicide of their loved one;

> *"about 6 months before he died, he started smoking heroin, you see that's what I think, he was getting into heroin and it was killing him, I think meself that he couldn't live with himself, "*

> *"he hated himself for being on heroin….. , he did say it to you [Ma] didn't he, he said 'You're never going to have to worry about me on drugs again"* *(the last words to his mother before he took his own life)

Living a life of addiction led to other high risk behaviours and resulted in the further traumatisation of the substance dependent persons, this mother recounts how her daughter was exposed to sexual violence due to addiction and homelessness;

> *"ya know and what goes with addiction you know and I'd say boys as well get raped but she was very badly raped" (**the person reference in this quote is not one of the deceased)

Drug related debts were a feature in the lives of families, particularly in more recent years where in the main young people were threatened, intimated and assaulted due to owing money for drugs, this father recalls how his teenage son was ;

> *"basically they brought him out to a woods, tied him to a tree and beat him up, but they were also the gang that were ringing the phone, driving up and down the house.. and threatening, there was a lot of intimidation going on"*

<u>The impact of use on the family</u>

Living with substance misuse can place a lot of burdens on family systems. All of the families provided an insight into the financial costs, and also the personal cost of dealing with the stress, strain and chaos of managing addiction. The financial costs primarily revolved around the addiction itself.

> **"***we had to bail him out with a huge amount of money and it took us years to pay it back"*

> *"it brings you down to earth very quick with the things t'doo and I always think looking for money or looking for this or looking for that, all the lies that you told me because I remember every one of them (…) they tell you everything and anything bar the truth and they take everything they can on ya, leave ya with nothing"*

There were also financial implications in relation to their loved ones health issues and fears about potential future costs such as potential funeral costs should their child die.

> *"it was 300 pounds at that time it was, to wait for the HSE it would have been over a year, I said *imitates herself* 'You're not going around for a year with no teeth' so borrowed 300 pounds, went and got the new teeth"*

> *"you could get a knock at your door tonight and it could be where are you going to get 2000 euro to bury them. I often worried about that where I'd get the money to bury them"*

Many families in the early stages of discovering addiction operated in a vacuum of support and found themselves trying to manage the situation and this brought huge pressure and responsibility.

> *"he was staying with me, and I'd be going out buying methadone off the street, trying to wean him off it"*

Families too were impacted by a sense of shame and isolation;

> *"you see what happens is like your other family like your own brothers and sisters and that they pull away from you a bit when your children is in addiction"*

Living with a loved one who is in active use brought chaos, but this was also set in the context of great love, and parents have to balance the love for their child while operating within the turmoil of active use. There is a push and pull conflict for parents who love their children and want to keep them safe while trying to cater to the needs of the broader family.

> *"I remember your man saying one night that his daughter you know she was living on the streets an all that and he got her home, and he was saying you know that he got her home and she was safe and on the couch and he put the blanket over her, and we all started crying you know, because we all that night that you got them in and you could just mind them"*

> *"see when he was here you'd have a laugh, it was worry, everyone was looking for him, did anyone see him, know here he was, and I would be saying don't lend him money, don't put him in your car, I'm telling you he'll leave stuff in your car and you'll be took in, you're going to be this that and the other, this is what I would be doing, the whole house was around him, do you know what I mean"*

> *"I couldn't have them here in case they'd leave the drugs around and then the grandchildren wouldn't be allowed come because if the social workers knew that you had them in the house, I use be always afraid that"*

Research has identified that parents bereaved by substance misuse are impacted by more physical and mental health implications, interviewees in this study reported an array of health issues which they attributed to the trauma of losing a child in this way;

> *"I had a brain haemorrhage and ah after [my son] dying they said it was the stress that caused it"*

This husband and wife reflect on the impact of losing children due to substance related death, when talking about the importance of self-care;

> Wife: *"yeah you know you realised that after with [our son] because he (points to husband) you ended up having some mini strokes".* Husband: *"Mini Strokes, yeah mini strokes, I am going around with a stick now".*

> *"and this is your third time since [daughter] died, this is her third time with cancer"*

Experiences of services

Families who are living with addiction have a range of services to navigate such as health, justice, education, social services and addiction support services. In some instances there were hugely positive experiences however in others there were encounters with professionals that generated huge levels of stress and anxiety for families. Moreover, families reported that some of these experiences compounded what was already a very difficult situation.

<u>The Role of Support</u>

There was overwhelming consensus that peer support provided families opportunities to share knowledge and experiences that aided with decision making, navigating relationships and self-compassion.

> *"ah coming up to his anniversary she always gets real distant or she might go away or she might cause trouble or she's always doing something, do you know that kind of way, and its gas cos someone in the group will have had it and they will give me the support, they will say 'that one was like that with me and cos I think it's like the end of the world cos the kids you know"*

> *"after [our son] died that changed our lives, we started out on a different journey in life, we got to a crossroads with all this addiction, for 20 years, more, for 25 years, we were trying to juggle things around in life you know trying to hide things trying to control their addiction and we didn't really achieve anything you know but when M died it changed our view on things, we found a group here and we started getting involved, our journey, this crossroads took us on the right road"*

Perhaps the biggest impact of the peer support services was the effect these groups had on an individual's grief process, often helping people to move from shock and anger to peace and acceptance. There was a sense of complicated grief that saw family members caught in stages of anger or disbelief and having a safe space to process and move through the natural stages of grief provided an immense feeling of release and healing.

> *"I went up to the bereavement group up in [NFSN] I honestly don't think I'd be the person I was because ya see I didn't handle it very well when she died I started drinking, not every day drinking that's not the way it was but I was drinking more than I was, I felt I couldn't grieve the way I wanted to"*

> *"now through the family support because they do a grief service right and I did the ten week of that and after I was able to say I wouldn't have [my son] back now because I am happy with where he is, cos you know if he was here and going on with heroin and the life that he was leading I'd say he was you know going to end up you know in really bad crime and drugs and that, so if he is where he is and in no pain and happy sure that's all a mother wants for their kids do you know what I mean so"*

> *"and now [my daughter] she's getting grief counselling over in [name of service] you know and she talks to me all the time now, she will talk"*

> *"and I really only dealt with my pain about *pauses* four years ago, which, three or four years ago, when [NFSN] set up this bereavement group, and she came in and she did the course, and I swear to God, I cried, and cried, and cried for weeks"*

Families also make reference to times where they had been referred to counselling services that had not worked for them, mostly the sense was "*not the right people, not the right time"*, and there were reports from families that they felt judged or not understood. It appears from this research that the appropriate and most useful services were bereavement supports specific to substance related death. This is not unexpected considering the notions of *blame, shame* and *stigma* that have been referenced in the interviews.

A health issue or a criminal justice issue

The narratives of the families detail quite a complex tension between the health needs of their loved ones and the fact that much of their drug and/or alcohol behaviour led to criminal activity and ultimately contact with agents of the justice system whether they be Gardaí, the courts, probation and/or prison. Drug taking is an illegal behaviour that is responded to as such, however the criminal justice system has neither the capacity nor the remit to consider the health issues of substance misuse. Many families reported that their loved ones had been exposed to traumatic events which had adversely impacted their well-being and all families felt that substance use was linked to mental health but was not treated as such;

> *"People who, who really struggle with mental health and they use drugs and alcohol to cope with that"*

Conversely families reported that this tension at times compounded the situation for their loved ones;

> *"[my brother was] trying to get his life back on track but the Guards wouldn't let him alone remember?"*

> *"But when I do see the police out there now with the young fellas, they are a different kind of police to when, I swear to God, when I hear the way they speak to those young fellas out there and it's fucking disgusting"*

Four of the families interviewed complained that their young people had a very negative relationship with the Gardaí and that there was a failure to see their children as struggling and acting out due to poor mental health;

> *""I think there's a lot of areas in Ireland that need to be addressed, like we'll say the Guards having power trips and not having an understanding of the vulnerability of the young people, because their emotional state is in a growth stage"*

One participant queried whether this was an issue confined to inner city Dublin;

> *"it's not acceptable to me, but we accept it, we let this go on, they drive down the street and they are on the speaker, 'good evening scumbags' and the young fellas laugh, do you think if this was Blackrock or Foxrock that they would carry on like that"*

However a similar experience was also reported in a rural area as reported by this father who stated that the difficult relationships between Gardaí and young people created a self-fulfilling prophecy that prevented young people from progressing;

> *"some Guards would just write him off *Imitates guards*, 'He's a scumbag, that's it'. And would treat him accordingly, which (…) you treat any (…) ah, delinquent like a thing an that's what you'll get back"*

The children's court service was also identified by a mother as being unconstructive, there was a sense that the processes were not cognisant of adolescent development and only exacerbated the problem by criminalising vulnerable young people who are struggling with addiction and/or mental health;

> *"but I'm not being funny but why are they all here, he's not bleedin' Ireland's most wanted', he was really buzzing off them and they were buzzing off him, it was like, 'see the 7 Garda there Ma' and you could hear all this you know"*

There was an acceptance among families of how their loved ones' behaviour was problematic but also frustration that loved ones were marginalised and criminalised and that these spaces did not facilitate room for growth and recovery, there was a clear need for multi-agency collaboration identified;

> *"well [my son] was seeing a psychologist and she washed her hands of him when he wasn't playing ball, the juvenile liaison officer washed her hands of him, you know there is something wrong in a system that can adopt that attitude, because these are kids at risk"*

> *"and I mean they are a nuisance to society, but it doesn't go away, it just, pushing them to one side is not the answer, somebody has got to take control of the situation and say you know these people need help right, they need, if you are an alcoholic or a drug addict you are marginalised, you are separated from society, you know here's this drunk in again and the problem is that people don't really understand what these people are going through"*

> *"but there is so much a thing of mental health issues and suicide in Ireland why would you not want to address that, you know it's becoming worse and worse because the services aren't there as such, like you can access them eventually, but eventually isn't actually when you need them to be there"*

Navigating Services

The multitude of services that are traversed has already been mentioned and families had extensive and insightful feedback on what works well and indeed what could work better. Many families were left feeling disillusioned with, or judged by services at best, and deeply distressed at worst. There was particular emphasis on addiction services, mental health services, social services and education. Almost all of those who had died were early school leavers, excluded for challenging behaviour. There was a feeling that no one service would case manage the dependent person and that services bounced individuals around to a point where they became excluded from mainstream services.

> *"I do believe that everyone deserves ten chances, twenty chances. You don't get one chance and that's it, especially where drugs are concerned you have to keep believin in them and telllin 'em and letting them know I believe in you, you can do this, there's not enough of that, it's like a revolving door"*

There was disappointment that schools were either unwilling or unable to support their young people to stay in education. Previous research has identified education as one of the biggest protective factors for young people (Murphy et al, 2017). There was feedback in relation to addiction services where many felt that the expectations that were placed on people who are substance dependent were not realistic and set them up for failure. There was a general call for more flexibility, compassion and individually tailored approaches to addiction treatment.

> *"I think meself personally all people who are using drugs are treated with the one treatment, and I think they should be treated as individuals"*

"People need eh yeno people on drugs yano they need more drug centres eh and not a waiting list yana yano drug addicts ringing up and saying "Have you got a bed? Got a bed today?" That's, that's wrong"

"kinda gave me a kick in the hole was me son that died. Ringing [treatment centre] for 18 solid weeks to get on a methadone programme, And if he missed one week, he were put right back again to the start of the list, So he kept makin' the phone calls, makin' the phone calls. And the day after he died he made it … [on the programme] but it kills me here all the time (holds his chest) why he couldn't get in down there he had to wait, that really hurt me like, he couldn't get on that programme he wanted to, he really wanted to."

While this report has already referenced the debate surrounding whether drug misuse should be a criminal justice issue or a health issue, families struggled to navigate the mental health systems;

"So eventually we got back to [hospital] and they said, there was a different doctor there, and he said 'No we're not taking her' and at that stage I went ballistic, I said 'you're not taking her after me sitting for 24 hours in the hospital, I did what ye asked me to do, we got the information that was needed and now you're not taking her"

There is considerable debate currently about the concept of Dual Diagnosis, (i.e. being substance dependent and having a mental health disorder). The consequence of this is that patients bounce over and back between addiction and mental health services with no clear structure for managing people who present with both issues (Wall, Lambert & Horan, 2017; MacGabhann et al, 2004) and it is argued that services working in parallel rather than in collaboration are failing the most vulnerable;

*"Because he was feeling suicidal, and I rang Doctor (name), and I spoke to her and I was out in the hall, the landline was out in the hall, and [my brother] was sitting on the wall, facing me in the little hall, and he said, 'and tell her this, and tell her that and tell her I'm coming off drugs' and she said 'Is he coming off drugs?' I said 'He's off heroin three weeks', I said 'That's not the problem, he's suicidal' *imitates doctor* 'Oh we don't deal with drug cases' and I'm like, 'But he's suicidal' *imitates doctor* 'Yeah but, no, you'll have to get him to go to a drugs place'. So the next day I ring her, was it, it was the next day wasn't it, a couple of days after, I rang and I asked her, and I said 'I rang you the other day about me brother' She said 'Oh how's he getting on?' and I said 'He's fucking dead' and I just hung up the phone, that was the end of it then, but I was very very angry at her, really angry at that, you know"*

The role of social services in peoples' lives also presented tensions. While families understood that social workers were assigned to provide support and assistance they also felt powerless and at times punished. There was a dilemma in dealing with social work, it was difficult to be honest about possible struggles and difficulties and reaching out for support in case this would be used against them at a later date.

"the children that he had, there's two of them, there's one of them in care now, I'm not good (cries) there's one of them in care, we were condemned, any your grandchildren are going [into care] it's like this you'll do what we tell you, you don't deserve those children, you'll do what we tell you"

In the following extract this husband, wife and their daughter reflect on their experiences, they reported that they felt stigmatised by a social worker, like they had failed as parents and now as grandparents;

Dad: "we were getting punished"

Mum: "and we were trying to keep a family together you know trying to keep..."

Dad: "them in the one area"

Mum: "you know trying to be grandparents"

Daughter: "to be a support for the grandchildren"

Discovering death

The families who participated in this study recounted the moment that they discovered the death of their child, the deaths were traumatic and sudden. Only one death was anticipated and not sudden as it followed a long battle with liver failure, however this did not mitigate against the impact. One sudden death by overdose occurred abroad which added to the strain on the family. Two loved ones were found dead in their family home while three men died in hostels.

<u>Self-blame and failure as a parent</u>

Interviewees recounted in vivid detail the moments when they either discovered the body of their loved one or when they were informed of the deaths by others. While there was always a fear that death could occur when it did there was overwhelming sense of shock for all. In the initial weeks, months, and in some circumstances years, many parents blamed themselves and also felt blamed by others.

"See none of me Da's family knew that he was on drugs, he was devastated having to tell them because I think it was like my Da felt the way he had failed"

"sometimes I feel like I deserve to be punished but its very hard to come out the other end, that's very hard when you don't understand that you didn't do anything do ya know what I mean? We didn't do, I didn't do anything you didn't do anything."

"and all the people from the area judged them parents because their son [was in addiction]"

The experiences of guilt, shame and self-blame are similar to findings that have published in the literature in relation to parents who have lost children by suicide. N interesting observation was the parents' experiences with 'death professionals' or undertakers. Some families reported a sense of anger and disappointment when they reflect back on the organisation of their loved ones' funeral. They felt that their sense of self-blame was manipulated, and certain undertakers (only mentioned by Dublin interviewees) recognised a vulnerability and pushed the parent into picking very expensive funerals as the last act of love they could provide for their children. This is worth exploring in a separate study as differences between the rural an urban participants were clearly identified.

Peace in death

There was a complicated juxtaposition for families, there is a balancing of emotions between the pain of loss and a relief that their loved one is now safe in death. Living with active use had caused huge worry and stress for families, and they constantly worried for the safety of their child. However most families interviewed had a belief in an afterlife and found comfort that their child was now at peace.

> *"he wanted to die I think because his life was just destroyed, he had lost his family he had no life at t'all, he had no legs, his arm was gone, he was angry, he just couldn't get himself together at all do you know what I mean, it was a blessing for him you know that he passed on"*

> *"and P says Ma I'm glad, cos he could have ended up getting killed on the streets and he didn't suffer so he said I am happy with that so"*

> *"Because you won't be worried about them anymore"*

> *"now when [my son] died it did break me heart but thanks be to God I knew where he was gone and maybe taken before he's worse. I knew where he went I was very happy. I didn't like him to be gone but I knew where he had went"*

In every home visited family members had used the services of mediums or psychics to get further reassurance that their loved one was at peace. While most felt that visiting mediums had provided comfort, it wasn't without its complications;

> *"After [my brother's] death we all kinda got into like the angels and mediums and stuff, that I suppose you kind of, but it's like a phone call, ya know like"*

> *"I remember this one, one time, she was the greatest quack, when I think back, and [my son] didn't come to me, and I remember crying for about 3 days solid, I couldn't go to work, couldn't eat nothing, and I remember thinking he must hate me, really hate me"*

Special Death

Special deaths have been defined as deaths where there is increased impact on the individual, the family and society (Guy & Holloway, 2007). Special deaths are traumatic and have other compounding variables. This was evident in this research. The nature of addiction involves illegal behaviour so there are often secrets and lies, particularly by those who may have been using with the person at the time that death occurred. In some instances families still do not have a clear picture of the circumstances of their loved ones' death. There is the involvement of the coroner's court as the deaths are nearly always sudden and unexpected. There may be outstanding drug debts that drug dealers expect the families to pay. For some there is a double grieving process, they mourned the loss of their loved one when they 'lost' them to drugs, and now they must mourn the loss of a loved one lost to death;

> *"She was after saying (…) and we always talk about this, she didn't grieve for [our brother] when he died, she grieved for [our brother] when he went on drugs"*

Families also have to reconstruct the memory of their loved one as they will have experienced positive times with their child but also very negative times. In effect they have the memories of the child who

was in addiction and memories of life before addiction and these two versions of their loved one need to be aligned.

> *"I suppose there's two sides to it, there's love and there's heartache raring a child, so the love and the heartache, the heartache was stopped automatically, suddenly stopped ,so then you have to go back and pick out the bits you loved about him and knock out the other bits, that was very confusing do you know that kinda a thing but that would still be on going that I would be trying to"*

Life after bereavement

The loss of a child is hugely traumatic for parents irrespective of how that death may have occurred;

> *"I mean, your life just ends, the family just stopped, do you know as I said to you like we sit, I mean when I am in the house when they are all here that's when I miss him the most cos I'm really conscious that there's one missing"*

Mother's in particular recounted how they struggle with the loss, all those who died in this study were adult children, but to the mothers they will always be their children, as described by this mother in a very poignant quote;

> *"I would drive out to the grave, it was like I was making his bed, I would pat the whole thing down and fix it and everything"*

Disenfranchised grief

According to Doka (1989) disenfranchised grief is 'a loss that cannot be socially sanctioned, openly acknowledged or publicly mourned'. Disenfranchised grief complicates the natural grieving process with huge implications for those bereaved; not being able to legitimately grieve your loved one prevents the bereaved from moving toward acceptance and healing. This has consequences for the whole family system and is more likely to generate inter-generational trauma experiences as unprocessed grief permeates through the family system and other systems around the family. Families reported feeling disenfranchised within their communities;

> *"ah I will tell you why, ahm we went to two funerals of 2 young people that died and it just so happened that ah one of them, was of a couple out of our group lost their son and we were too early for the church because we weren't sure where the church was and we arrived there a half an hour early and hundreds of people were coming out of the church and when this young man's remains were being committed to the church there was about 20 people there. The two of them were the same age, that other young lad that died he was killed [in an accident]and everyone turned up, them poor parents never got over that, neither did we – because they came from the same street, the same area but one died from an accident and all the people from the area judged them parents because their son"*

> *"I know that I was the way I felt, I don't know how or whether this was just in me head or not that em (…) he deserved nothing better because he was a drug addict, this is the way it was coming*

over to me, that poor child there died of leukaemia God bless him and save him, but don't talk about this scumbag that deserved to die"

"there was nobody for me to talk to now the first time, the shame that is forced on ya because your son you know, you didn't deserve any of your feelings you know you didn't deserve to talk about him, you didn't deserve anything because he was a heroin addict or a junky as what they call them"

Families also reported that they felt disenfranchised by those who should have been in a position to support them;

*"But even the priest an' all nearly destroyed me Ma, even the priest, because the priest did say to her *imitates priest* "You know he'll never be in heaven"*

There were many examples where families felt disenfranchised within their communities, however this was even further compounded when the bereaved also experienced this within their own families. The following is an example of how for one family this still continues;

*"they know that they never even acknowledge an anniversary cos [my wife] does put it up on Facebook and light a candle and we have two plaques at home in the garden in ******** none of them would ever respond to any of that"*

The cycle of trauma

As previously mentioned disenfranchised grief has the potential to perpetuate the cycle of trauma through families. Additionally there is a transmission of the traumatic experience of the deaths themselves onto others, as fear and anxiety about the future potential for loss is projected;

"You know you project stuff with your grandchildren that maybe there's no need, you know its just ourselves sort of"

The cycle of trauma is experienced in the ways in which people manage grief;

"like my [son] is drinking 6 or 7 cans a night and now I am saying to him you know P that's how you are coping but you are not coping because you have to stop 6 or 7 cans and deal with the pain do you know what I mean because you can't, you can't be doing it do you know what I mean"

The whole family system is impacted by the traumatic experience of living with addiction, experiencing a sudden and traumatic death, and interviewees expressed particular concern for the dependent children who have been left behind. In the current study 8 children and 1 grandchild were bereaved. The children have experienced the loss of a parent, fractured relationships with grandparents, have entered the care system and were reported to have a range of psycho-social difficulties. Grace (2012) in her doctoral thesis outlined the consequences for children bereaved in this way; children with complicated grief reactions were perceived as 'bad' instead of 'sad'.

Stages of Grief

Much has been written on the stages of grief, Kubler-Ross and Kessler (2009), argue that there are five stages of grief; denial or shock, anger, bargaining, depression, and acceptance. The full gamut of these emotions was expressed by participants in this study. There was an interesting observation from the data, all of the parents stated that for 3 to 4 years after the death of their child they lived in a state of shock, and reported feeling withdrawn and numb.

This mother describes how she returned from work one evening about four years after the death of her son, her daughter says 'welcome home', the mother replies I was just at work, her daughter says '*no welcome home, you haven't been with us for four years*;

"welcome home, because for that four years I lived, slept, ate drugs, I went to every meeting, I got up in the night, I went to graveyards"

"the worst thing that can happen is wishful thinking, cos that's not reality and that will hit you like a brick wall, I went to J's grave every day for 3 years to remind myself that he was dead, cos every night I would sit here and wish that he would walk through that door and I went to bed like that so when I woke in the morning it was the worst rawest pain in my stomach when I woke up and that was the reality kicking in and I never never want to experience that again"

When asked by the interviewer in a discussion about faith and spirituality, if this mother could feel her son's presence around her she replies;

"yeah but that's only in the last few years, for about 3 or 4 years I couldn't feel him anywhere"

The following extract from a mother on the loss of her son by drug related suicide recounts how she withdrew from her family for about four years;

*"This is personally for me, I think it affected me whole family, ehm, I had three grandchildren when [my son died] and he left a letter saying you know you done your best and all that sort of stuff, make sure the kids don't go on drugs, help them, but I find now that instead of helping them *pause* I kinda neglected 'em"*

Younger family members reported the impact of their grief on their mental health, their social functioning and the fear of future loss.

"you have guilt you know and these things are all normal but when you are going through these things it doesn't feel normal, the guilt you know, what if I did this and what if I did that, and it's all what if's but as many people have gone through it, but when you are going through it you don't feel normal, maybe because I was so young that it had that impact but you know even looking back like I separated myself from my friends in school, I didn't want to be part of it cos I felt different, but they didn't know how to take me either"

"I think I only dealt with all that the last while as well, like I think I got very anxious, like anxious and all ya know, when you were going away [speaking to her grandmother] I used to sob, I didn't know if she was coming back"

Pulling apart

Bereavement literature talks about the impact of grieving on relationships, it is argued that relationships are renegotiated during the grieving process (Kubler-Ross and Kessler, 2009) however the impact of the loss can be so great that the relationship breaks down (Oliver, 1999). The families in this study highlighted the complex management of relationships in the period following their traumatic bereavements. At times relationships had broken down, there was also a more subtle 'pulling apart', where the family continue to co-exist but a silence surrounding the death was an invisible breakdown in relationships;

> *"I remember when I heard about [this project] you know about the impact on the family and I spoke to B and said I wanted to do it on me own and she said 'nah that won't do it's for a few of the family' and I said 'put me in for that reason and she said 'what' and I said 'that's the reason to put me in, cos that's another end of it"*

The lifestyle of the bereaved had already created division in families before death and this was further compounded after death as described here by a participant who has fragmented relationships now with his siblings following the death of their brother;

> *And eh, all me sisters n'all didn't have no time for it [their brothers' active addiction to heroin] to be honest with ya, And now we're feeling guilty, now so we are. Now we're feeling guilty. Too late now so it is, He's gone now. *sniffs* and eh I had murder with them there, couple of weeks ago, told them all to Ehm a few home truths"*

There was considerable heartache and struggle for many, particularly where access to grandchildren was an issue;

> *"now his children unfortunately haven't spoken to us since and we would love to have them back into our lives you know but there again you know we tried to reclaim the family but it's not to be because the mother has blocked it"*

> *"I feel, you know losing the grandchildren that's another loss I feel to us you know"*

This mother who lost her son has to carefully manage relationships with her sons' former partner in order to ensure continued access to her grandchildren;

> *"now I do see the kids all the time, now his girlfriend is as bitter as the day he died, she never went for counselling, she never looked after herself, never did anything, and she thinks because I have moved on that I don't give a fuck about [my son], she thinks because I have had counselling that I have worked on meself, so there can be a lot of arguing, so that's how I do me counselling is through the family support, that's where I am coming from, to deal with her to be honest"*

Lost years

As with all bereavement, particularly where a younger person has died, there is a grieving for the lost potential and a sadness surrounding future life events (Field & Behrman, 2003; Erikson, 1963). This is almost always a feature in substance related deaths, the Health Research Board's Drug Related Death Index for 2015 noted that the average age of individuals who died was 41 years old (HRB, 2017). In the current study the average age of those who died was 31 years old. The HRB's most recent report has for the first time started to record 'years lost' and noted that approximately 20,000 life years were lost in the period of 2015 due to DRD's (HRB, 2017). Years of Potential Life Lost (YPLL) is increasingly being used in epidemiological studies to highlight the future consequence of bereavement data by highlighting personal, social and economic loss (Joodi et al., 2017).

In all of the interviews in this project there were much time spent reminiscing, sharing memories of happier times, there was also an acknowledgement of the on-going experience of loss;

> *"and there's been other things like he would have been 30 and all his friends were 30 and they were all having big parties and I felt it, do you know that kinda way, its things like that"*

> *"but the effect that it has on our family has been, am, there's always been something missing at Christmas time, any family event [my brother] was always missing, if I am ever going to get married [my only brother] is going to be missing, there's a lot of things where we look to the future you know and he made his choice, but that pain, you know that pain just never goes and you know people say that time heals, time never heals you just learn to live with it, you learn to live with this new way of being because a part of you is gone and you are never going to regain that back"*

Healing through Activism

Meaning making has been identified as an aspect in the grieving process particularly when a parent loses a child (Neimeyer, 2000; AlUqdah & Adomako, 2017), it mitigates against current and future experiences of loss (Bailey et al., 2013), and has been referred to in the literature as 'political grieving' (Cheng, 2000). Grief inspired activism has been demonstrated in a range of socio-political spheres where parents advocate for social reform (AlUqdah & Adomako, 2017). Parents in the current study described how they used their experiences to advocate for assistance at political, social and personal levels;

> *"We were marching for nearly a year, taking to the streets, lobbying government ministers"*

> *"say helping others, when we go to a meeting it grounds us, it reminds us of how important it is to stay well and maybe our story might help people and we might be able to encourage people"*

> *"I felt I was doing something, for [my son], *pause* yeah I just poured all me life into it, for the last , *pause* *crying* , for the last twenty-one years."*

> *"Everything we do now, we try to give hope to everyone"*

The activism facilitated parents to push for socio-political change and at a more personal level it facilitated the support of peers. Engagement with peers gave huge hope for families as there is potential to influence change and this ultimately facilitated healing.

Feedback on participation in the research process

There has been some discussion in academic literature in relation to the ethical considerations of working with bereaved families. However research shows that while in telling the narrative there is of course sadness, and this is an appropriate response in the context of the story. However, the process is perceived by participants as a validation of their experience and as therapeutic (Dyregrov, 2004; Steeves et al 2001). The current project posted anonymous research feedback surveys to the participants and 12 were returned in stamped addressed envelopes. The survey consisted of 5 questions relating to the interview experience (see Table 2), comment boxes facilitated the collection of additional data should respondents wish to express additional information.

Table 2: Participant feedback on the research process

Question	Response	Total	Response	Total	Response	Total
Being involved with this project was:	Not Positive	0	Positive	2	Very Positive	10
The length of the interview was:	Too Short	0	Just Right	12	Too Long	0
During the interview I found it emotionally:	Very Painful	0	Painful	3	A little Painful	9
In the days after the interview I felt:	Worse	0	The same	1	Better	11
Doing the interview helped me understand more about other family members:	Not at all	0	A little	4	A lot	8

Other comments were provided and these can be grouped into themes, all comments provided have been reported. Participants reported that being involved with the project was positive, stating it may facilitate helping others in the same situation or assisting the organisation that had supported them. This is consistent with a theme identified in the interview data, grief inspired activism has been identified as a beneficial activity to alleviate the feelings of loss (e.g. AlUqdah & Adomako, 2017).

> T*he most positive part was to get our story out that can help other families get the support for themselves*

> *The most positive aspect for me as the knowledge that recounting my sons life and death might in some way help in the future to avoid in someone's decision to take their life and maybe identify what makes suicide the cure all to anybody's problems in life*

> *I hope by doing this that the NFSN will get the funding they deserve because a lot of parents who have lost loved ones to addiction depend on the great work that the NFSN have done over the years*

The therapeutic value of a family interview was noted, participants found it useful to hear other family members views and to recognise that different people grieve in different ways and at different paces. However, there appears to be limited research on the role of family therapy in bereavement.

> *Really enjoyed talking with family and getting insight as to how they feel*

> *Hearing other family members opinions*

> *I found the whole interview helped me understand how everyone goes through grief differently*

> *I found this interview very interesting, even listening to my dad's experience. I thought the interview in my dad's house helped to feel more comfortable. This interview helped me to check into my own life and also see how far we have come since (my brothers) death but also to see how much his memory lives on through us*

The location and opportunity to speak was important to many respondents particularly those who had not discussed the loss of their loved before, it appears that the opportunity to speak was therapeutic, the fact that it was facilitated in the persons' home enhanced this opportunity.

> *I was glad to speak to you cause I don't like to go somewhere to talk, it was nice it happened at home*

> *In the beginning it was sad and not good but as I got into it it was good that was the first time I talked about them things since my son died, I would like to go and talk to someone again*

> *It was most positive for me as I bottled a lot of anger and resentment over the death of my son and this was the first time I ever spoke about his death openly and it has lifted a lot of my mind.*

4. Discussion

The experiences of families who have been bereaved due to substance misuse related death is a largely neglected area (Guy, 2004; Templeton et al., 2016). This is despite rising trends in addiction and in drug and alcohol related fatalities. Research is very limited with only a handful of studies globally (Templeton et al., 2016), and the current study is the first of its kind in Ireland, it is also the first study globally to interview multiple members of one family. This current study interviewed 7 families and included 17 bereaved. The results highlight the adverse impact of addiction on families before and after the death of their loved one. The data generated four themes; living with use, experiences of services, discovering death and life after bereavement. The impact was felt financially, physically, psychologically and socially. The true cost is difficult to quantify as we have no data on how many individuals are impacted by each death. There is the immediate family of course, but there are also the staff of the associated services (e.g. homeless services) and the social network of the person who has died, some of whom may have been present when death occurred. The impact on the wider circle should be researched. What is clear is that the cost is felt at both a personal level and a societal level, it is in a government's best interest to urgently address this issue due to the economic and personal burdens, there are costs borne by health, justice and social services.

The findings of the current study encompass the lived experiences of families who have been impacted by living with active addiction and subsequently traumatic bereavements. The first theme identified in this study was 'living with active use'. Families detailed harrowing accounts of the impact on both the substance misuser and the family. It is clear that support for families is required to mitigate the impact financially, socially, physically and psychologically. Many families in the early days of managing their loved ones' addiction did not seek support due to shame and found it difficult to locate appropriate supports. In at least two of the deaths featured in this study the stigma and shame of drug use was a contributing factor in death by suicide. One of the biggest factors that prevents people accessing psychotherapy is fear of stigmatisation (Vogel et al., 2007), this is further compounded when substance misuse is the presenting issue (Myers, Fakier & Louw, 2009). A public campaign that challenges this stigma would assist families to access early intervention and possibly reduce the adverse consequences and risk of death associated with substance misuse (Lloyd, 2010).

Families and their loved ones had mixed experiences of services; there was a general consensus that many of their experiences involved trying to navigate the 'revolving doors'. The new Irish National Drug Strategy 2017-2025 aims to have a health led response to substance misuse, however this will only be possible if there is meaningful engagement by all stakeholders with robust policies and support to shift drug use from a criminal justice issue to a health issue. Responding to the needs of substance misusers and their families requires a multi-agency approach; education, health, justice and social services. All of the relevant agencies require a review of their current strategies for responding to addiction and whether their strategies are supportive or obstructive to growth and recovery. All of the agencies and stakeholders need to take a shared responsibility for the issue and utilise the existing Rehab frameworks. The National Drugs Rehabilitation Framework Document already provides for inter-agency shared care plans (Doyle & Ivanovic, 2010), however support for this framework has been mixed across the agencies. The new National Strategy does not contain a young persons' specific section; it is clear that more efforts are required in early intervention and keeping young people in education. The Department of Education should consider its responses to young people who are marginalised and struggling, and develop systems and structures that can respond to their needs. Schools have become more proactive in responding to the mental health needs of young people and this should be extended to include substance misuse as a mental health issue. Reframing substance misuse will facilitate the reduction of stigma and the marginalisation of these young people thus creating compassionate and supportive environments. It was also clear from the interviews that an educational campaign is required in some sectors, the responses of services to substance abusers and their families was perceived as obstructive and punitive and at times served to compound their difficulties.

All of the families reported that their loved ones had experienced trauma either before or during their addiction and were at times critical of addiction services ability to meet the needs of those presenting. Interviewees stated that some addiction services had unrealistic expectations of substance misusers' abilities to manage services in the midst of their addiction and these hurdles prevented people from accessing services. There is increasing evidence of the relationship between trauma, mental health and addiction (Huckshorn & LeBel, 2013; Lambert & Gill-Emerson. 2017). Operating trauma informed services can increase engagement with services and thus improve outcomes; this should be explored across all human behavioural services (Harris & Fallot, 2001; SAMHSA, 2014). There were positives reported in relation to services, these were in the main services operating in the NGO sector. Participants in this study were recruited through the National Family Support Network and they were highly positive of the role of family support services. It was reported that these family support services provided peer support, sharing of knowledge and experience. Moreover, engagement with the services facilitated acceptance and forgiveness and grief and healing. The importance of this support to individual wellbeing and family functioning cannot be underestimated.

In recent times both research and practice has identified suicide as a 'special death'; where there is additional impact on individuals, families and society. The literature and practice recognises that 'special deaths' require specialised services in order to mitigate against the impacts of disenfranchised grief and this has been facilitated in cases of death by suicide where specific bereavement services have been established (Hawton & Simkin, 2003). When a death by suicide occurs there are systems in place to respond at individual and community levels, however no such systems are in place for DRD's. This study would argue that substance related deaths are indeed 'special deaths', this is in line with previous work by Guy and Holloway (2007). Every family in this study experienced disenfranchised grief, where normal grieving processes were complicated and supressed within families and communities. Disenfranchised grief generates unresolved trauma within family systems and permeates the whole system, family members in this study worried about the impact on future generations. A noteworthy observation from this study was within every family that participated in this study there were family members who were discussing their loss for the first time ever, despite the fact that some of the deaths had occurred over twenty years ago. A number of family members reported that they were glad to have been given the opportunity to speak and only did so because the researcher visited the home. It would be useful to explore this more to determine what is required to support those who do not access any services, a number of individuals did state that they would have welcomed a bereavement support worker visit to their home in the weeks and months after their loss but no such service exists. The issue of dealing with 'death professionals' in Dublin was raised by participants, there was a sense that some undertakers would take advantage of a families vulnerability and use the situation to push expensive funerals on families in an attempt to hijack the families sense of guilt. There appeared to be an urban-rural divide here as rural participants did not report this issue.

This should be investigated further. It was clear that specific bereavement supports are required for the whole family. Services should be funded to provide bereavement groups, family therapy and child centred grief counselling.

The literature has already identified the impact on children bereaved in this way; Grace (2012) demonstrated how children were perceived as 'bad' and not 'sad'. Children in particular are vulnerable to the impact of this trauma and stress in families, Felletti et al., (1998) in the seminal Adverse Childhood Experiences (ACE) study identified the health and social costs for children exposed to negative life events. The ACE study identified ten items that are demonstrated to adversely impact a child's development and children in this study are likely to have experienced four of these ten; living with a parent with a mental health issue, a parent with an addiction, an incarcerated relative and death of a parent. It has been argued in the research that a score of four on the ACE scale is clinically significant for increasing risk of future negative health outcomes (Murphy et al., 2014; Felletti et al., 1998). The future health and social risks for children in these situations cannot be underestimated and it is imperative that immediate and appropriate intervention occur. Funding community based services that can provide trauma informed services to the whole family system is urgently required. However if the stigma and shame of substance misuse is not addressed within all services this will reduce the efficacy of any programmes.

The study is not without its limitations, although the first of its kind in an Irish context and the first study globally to interview families, this study has a relatively small sample size. The experiences of the under age eighteen have not been heard. There was much criticism of external agencies responses to families impacted by DRD's however this study did not have the scope to gain other stakeholder views.

Future research should seek to;

- Determine the numbers of people impacted by each substance related death, within the family, within the social circle of the substance misuser and within supporting services
- Qualitatively and quantitatively measure the impact on children bereaved by substance related deaths
- Measure the impact of bereavement support on individual wellbeing and family functioning.
- Complete an analysis of the policies and practices of a range of identified stakeholders and services such as education, justice, health and social services.
- Investigate reports that 'death professionals' capitalise on a family's guilt and grief by encouraging expensive funerals beyond the reach of the family.

5. Conclusion

The current study outlines the impact of substance related deaths on families. There are harrowing accounts of grief and trauma, and a clear sense of a neglected and overlooked pain. It is not clear why this large group have been ignored within the literature, and this lack of recognition extends to policy and practice. Family members in this study reported disenfranchised grief, where their loved ones' death is not acknowledged or is devalued, this appears to be reflected in research and practice also. In Ireland, it appears that the only support provided to families who find themselves bereaved due to substance misuse and related issues is by underfunded grass roots organisations that could not possibly meet the demands of the families with their limited resources. There is stigma and shame associated with addiction; people experiencing difficulties with substance dependence are marginalised and powerless. As a society we are in the same space with addiction as we were twenty years ago with issues like sexual abuse, mental health and suicide. Historically these topics were taboo and individuals who had experienced these issues were seen as blameworthy, a veil of secrecy and shame prevented people from seeking help. It appears that addiction is a taboo, it is laden with moral judgements with little effort to understand the behaviour as a response to trauma, mental health and/or deprivation. Considerable change has occurred in how we respond to traditionally taboo areas like suicide, mental health issues and sexual abuse, instead of shame there is now compassion and support. For example, there is significant investment by government in the area of suicide, yet in 2015 the numbers of people who died due to a Drug Related Death was 270 more that those who died by suicide. It is therefore incumbent on governments to address policy and practice issues in relation to the area of addiction, a major health burden in current society. This requires investment in services, challenging stigma and a robust strategy that spans multiple domains such as justice, education, health and social protection.

6. Recommendations

- ✓ Fund and provide specialised bereavement support programmes for the whole family, this may require an outreach support for those struggling to access services.
- ✓ Urgent investment required in early intervention for children living with substance misuse and appropriate supports for children bereaved in this way. The impact of these adverse experiences on child development should be addressed.
- ✓ Support and training for parents and care givers of children who are impacted by substance misuse. The impact of stress on development should be communicated.
- ✓ Encourage services to utilise the National Rehabilitation Framework for inter-agency shared care planning. All relevant stakeholders (justice, health, mental health, education, addiction & social services) should engage
- ✓ Dual Diagnosis appears to be a specialised service rather than a mainstream occurrence. There should be a clear national policy in relation to the roles and responsibilities of addiction service and mental health services management of people presenting with co-morbidity of mental health and addiction
- ✓ A national media campaign is required to challenge the stigma surrounding addiction, where it is clear that substance misuse is a health issue.
- ✓ A robust training and awareness programme for front line services and professionals on the trauma and shame of addiction. The needs of substance misusers and their families should be communicated to all professionals likely to encounter this population.
- ✓ Provide access to research funding to address the current gap in the literature.

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Appendices

National Family Support Service: Research Feedback

1. Being involved in this project was:

Not positive	Positive	Very Positive

2. The length of the interview was:

Too short	Just right	Too long

3. During the interview I found it emotionally:

Very painful	Painful	A little painful

4. In the days after the interview I felt:

Worse	The same	Better

5. Doing the interview helped me understand more about other family members:

Not at all	A little	A lot

Please tell us what was the most positive and most negative part of doing the interview for you:

Is there anything else you would like to add:

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