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# Institute of Health & Wellbeing

## Identifying grief in parents who have had children removed from their care within Addictions Services: A pilot study.

**A Clinical Research Portfolio** 

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BSc (Hons) Applied Psychology

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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#### **CHAPTER ONE**

## Exploring women who misuse substances experiences of being a mother: A qualitative systematic review using meta-ethnography.

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Prepared in accordance with Addiction Journal guidance for publication (see appendix 1.1).

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#### ABSTRACT

**Background:** Parental substance misuse has a significant impact on a child. Previous research has mainly focused on risk factors and reducing harm to children. Qualitative research has begun to explore the experiences of mothers who misuse substances from their perspective.

**Aims:** This systematic review aimed to review the qualitative literature on mothers' experiences of being a mother who misuses substances.

**Methods:** A systematic search was conducted within suitable research databases to identify qualitative studies that explored mothers' experiences of being a mother who misuses substances. A quality-rating tool was used to assess the quality of the papers prior to synthesis. Meta-ethnography was conducted on six papers using a reciprocal translation approach.

**Results:** All participants were drug-users. Reciprocal translation identified seven major themes; (1) unplanned pregnancy anxiety, (2) child as motivation, (3) ambivalence between hope for parenting and guilt for consequences, (4) minimal parenting, (5) separation, (6) intervening factors–social support and recovery strategies, and (7) redefining the maternal identity.

**Conclusions:** The synthesis identified the processes that mothers experience in being a mother with substance misuse issues. These processes do not occur in a linear fashion. However, they can assist clinicians in identify mothers' experiences and utilise more effective use of evidence-based strategies, such as motivational interviewing, to improve engagement with substance misuse recovery and maternal role development.

Keywords: substance misuse, mother, child, experience, recovery

#### **INTRODUCTION**

#### The lives of mothers who misuse substances

It is estimated that around 4-6% of children in Scotland are impacted by parental substance misuse (Advisory Council on Misuse of Drugs, 2011). A UK study has identified that substance-dependent mothers experience a range of psychological, economic and social challenges (Powis, et al., 2000). The lives of these mothers are complex with poly-substance use and severe dependency, and substance dependent partners with a third of cases experiencing intimate partner violence (Powis, et al., 2000). Poverty means increased risk of criminal activity to obtain money, and nearly half reported treatment for a psychiatric problem with a fifth reporting suicidal thoughts (Powis, et al., 2000). Thus women are mothering in a complex context that impacts on their experiences.

#### Impact of substance use on parenting

This context has implications for mothers parenting practices. Previous qualitative research has found that mothers who misuse substance could identify their own negative parenting practices; such as exposing their children to harm with their behaviour, not spending time with their children, being unsure how to use discipline, and spending money on drugs over household goods (Brown, 2006; Baker & Carson, 1999). Mothers protect themselves against these negative practices by identifying they are also 'good mothers'; meeting their children's practical needs, protecting them from harm, and avoiding their children seeing their drug use (Brown, 2006; Baker & Carson, 1999). Children can be a barrier or a motivator for mothers. One study found that mothers experience a strong desire to keep their children thus are motivated to engage with services (Sun, 2000); however, another study found the guilt and shame around feeling a failure as a mother was a barrier to successful treatment (Ehrmin, 2001).

#### Social services involvement and intergenerational cycles

As a result of poor parenting practices and substance use, involvement of child protection services is common. Powis and colleagues (2000) identified that a fifth of substancedependent mothers had at least one child removed by the Local Authority. A qualitative study focusing on mothers' experiences of child removal found this experience was traumatic for mothers (Kenny, Barrington & Green, 2015). The Pause project works with mothers to break the cycle of having multiple children removed from their care (Pause Project website: <u>http://www.pause.org.uk</u>). Children who are removed become care-leavers. They have poorer outcomes compared to their non-looked after peers, including; risk of homelessness, poorer education outcomes, increased risk of mental health problems, criminal justice system involvement and risk of teenage pregnancy (The Scottish Government, 2013). As a consequence, intergeneration cycles of child removal can occur as the removed children are at greater risk of having their children removed (49% mothers care-leavers; Pause feasibility study, 2013). Understanding and meeting the needs of mothers who have had children removed could help break these intergenerational cycles.

#### **Developing a maternal identity**

As well as caring for a child, having a child involves the development of a new identity as a mother. Mercer's (2004) concept of becoming a mother identifies four stages to developing a maternal identity:

- 1. The mother building attachment and commitment to her unborn child and prepares for their arrival.
- 2. The mother is learning and becoming acquainted with her infant.
- 3. The mother develops a new sense of normal creating her mothering to fit with her other roles and learning to care for her infant.
- 4. The mother has successfully developed her maternal identity.

There are a number of ways that substance misuse likely impacts on the successful attainment of a maternal identity. As previously highlighted, mothers who misuse substances often spend little time with their child (Brown, 2006; Baker & Carson, 1999), which likely influences the process of becoming acquainted with their infant. Maternal identity also develops in a social context. Focus group research exploring substance using mothers perceptions of scenarios where services were involved, identified four discourses; "bad mother', 'good mother', thwarted mothers' and 'addicted mother'" (Reid, Greaves & Poole, 2008, p.216). Thus it is likely that mothers find it challenging to build a maternal identity whilst also experiencing societal stigma of being a bad or addicted mother. However, building a positive sense of self has been identified as a key process in mother's recovery from substance misuse (Sword, et al., 2009).

#### Purpose of this review

This paper aims to systematically review the qualitative literature regarding mothers' experiences of being a mother with substance misuse problems. Research indicates that being a mother occurs in a complex context with substance misuse impacting on parenting practices and carrying an increased risk of child removal. These factors likely impact on how mothers develop their maternal identity. Reviewing the qualitative research allows us to explore directly mothers' reported lived experiences of being a mother and how this interacts with their substance use.

#### METHODOLOGY

#### **Search Strategy**

The following search was carried out from March to April 2017. The database selection and search strategy was developed following training and consultation with a National Health Service librarian. The search was run in PsychINFO, EMBASE, Medline, CINAHL, Psychology and Behavioural Sciences and ASSIA (Applied Social Sciences Index and Abstract). There was no time limit placed on the search strategy, as the researcher believes there has not been a review conducted previously.

#### Search Terms

The databases were systematically searched using key terms for the four core themes: 'mother', 'drug/alcohol abuse', 'experience of mothering', and 'qualitative research'. Relevant search headings were used where the database interface allowed. Within each theme the Boolean operator OR was used to group terms and each theme was combined with AND. (See appendix 2.1 for detailed search strategy.)

#### **Inclusion Criteria**

- The study has clear qualitative methodology and analysis (e.g. methods including interviews, and analysis such as thematic, content, discourse, and grounded theory).
- Mixed methods papers if distinct qualitative analysis.
- Participants were mothers who have problems with substance misuse.
- Focus of paper will be their experiences of becoming, or being, a mother.
- Paper in English Language.
- Paper published in peer-reviewed journal.

#### **Exclusion Criteria**

- Studies with quantitative methodology and analysis.
- Studies that do not report the type of qualitative methods or analysis.
- Participants who are not mothers (e.g. fathers, staff).
- Focus of paper not about experience of becoming a mother.
- Studies where population selected for its comorbid presentations with substance misuse (e.g. gangs, prostitution, forensics).





#### Procedure

See figure 1 for diagrammatic illustration of the procedure following PRISMA-P guidance (Shamseer, et al., 2015). The search strategy resulted in a total of 2,340 papers (see appendix 2.2). A title screen, followed by an abstract and full text screen, was conducted utilising the inclusion and exclusion criteria. The reference lists of the studies remaining were hand-searched. Seven papers were identified.

#### **Quality appraisal**

Walsh and Downe's (2006) checklist was used to assess the quality of the papers prior to synthesis. Their checklist includes eight stages, with each stage outlining essential criteria with a list of specific prompts to guide assessment of quality (see appendix 2.3). Walsh and Downe (2006) warn against the rigid use of quality tools, stating that they included papers in their synthesis that adequately met their essential criteria. Therefore, the researcher decided that an essential criteria was adequate when 50% or more of the specific prompts were covered. To ensure reliability of appraisal, four of the seven papers were read and rated independently by a second rater (Trainee Clinical Psychologist) and differences discussed. The raters agreement on essential criteria for each paper being adequate/inadequate was good (96%).

Six studies were deemed adequate at quality appraisal and included in the final metasynthesis (see table 2). Brudenell's (1996) study was excluded as both raters agreed the interpretation was inadequate. The themes had limited use of verbatim quotes, which was felt would risk flawing the synthesis. Four of the six included studies had inadequate reflexivity. Reflexivity is attending to the context that the qualitative research is created in, mainly the impact of the researcher, such as recognising that the researchers background and beliefs can influence and bias the research from conceptualisation to findings (Malterud, 2001). The inadequate reflectivity in these studies may be due to the limited word counts provided by journals for publication (Walsh & Downe, 2006). If the researchers did lack reflexivity their findings are less transparent and may be biased by researcher opinion (Walsh & Downe, 2006).

**Table 2**: Outcomes of quality rating using Walsh & Downe (2006): eight stages (in bold)and essential criteria listed.

	Silva, et al. (2012)	Haritavorn (2016)	Secco et al (2014)	Cleveland, Bonugli & McClothen (2016)	Sorbo, Beveridge & Drapeau (2009)	Hardesty & Black (1999)	Brudenell (1996)
Scope and purpose –							
(1) Clear rationale for research	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(2) Contextualised by previous	Yes	Yes	Yes	Yes	Yes	Yes	Yes
research							
Design –							
(1) Methods clear and appropriate	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(2) Data collection strategies clear	Yes	Yes	Yes	Yes	Yes	Yes	Yes
and appropriate							
Sampling Strategy –					Case		
(1) Method appropriate	Yes	Yes	Yes	Yes	study	Yes	Yes
Analysis –							
(1) Approach appropriate	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Interpretation –							
(1) Context described	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(2) Clear audit trail	Yes	Yes	Yes	Yes	Yes	Yes	No
(3) Data used to support	Yes	Yes	Yes	Yes	Yes	Yes	No
interpretation							
Reflexivity –							
(1) Demonstrated	No	Yes	No	No	Yes	No	No
Ethical Dimensions –							
(1) Demonstrated	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Relevance and Transferability –							
(1) Evident	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Included further in synthesis	Yes	Yes	Yes	Yes	Yes	Yes	No

#### Synthesis Approach – Meta-Ethnography

There has been an increase in recognition of the importance of synthesising qualitative research. It is well placed to support quantitative findings by providing greater understanding of the context, thus informing implementation of service development (Campbell et al., 2011). In Campbell and colleagues (2011) evaluation of meta-ethnography, they state; "There are no standard or agreed methods for conducting synthesis of qualitative research" (p.3). However, meta-ethnography has become the leading approach to qualitative synthesis in health settings (University of Stirling & NHS Quality Improvement Scotland, 2011) as it is one of the best-developed approaches and has an interpretive underpinning in line with most qualitative research methods (Campbell et al., 2011). Following reading of Noblit and Hare (1988) the researcher chose to use meta-ethnography.

Noblit and Hare (1988) developed meta-ethnography to improve integrating and interpreting multiple qualitative studies. There are seven phases to meta-ethnography (see table 3). Noblit and Hare's (1988) described several ways to compare studies with the process of reciprocal translation for studies that are about similar things. Repeated reading of the studies (phase 3) confirmed that this was the most appropriate approach for this synthesis. This involved listing the metaphors/concepts that fully explained each study (phase 4). These were then translated into each other (phase 5) with Noblit and Hare (1988) describing this process as "one case is like another, except that..." (p. 38). This process was followed adding one paper at a time to the synthesis until all the papers were included (Campbell et al., 2011; 2003; see table 4).

Phase 1	Getting started
Phase 2	Deciding what is relevant to initial interest
Phase 3	Reading the studies
Phase 4	Determining how the studies are related
Phase 5	Translating the studies into one another
Phase 6	Synthesising translations
Phase 7	Expressing the synthesis

 Table 3: Meta-ethnography phases (Noblit & Hare, 1988; pp.27-29)
 Page 1988

(2011, p.57)					
Paper 1:	Paper 2:	Synthesis			
Key concepts	Key concepts				
А	a	Finding A and a (papers 1 and 2)			
В	b	Finding B and b (papers 1 and 2)			
С	d	Finding C (paper 1)			
		Finding d (paper 2)			

**Table 4**: Example of reciprocal translation as described by Campbell and colleagues(2011, p.57)

#### RESULTS

#### **Characteristics of the Studies Included**

Studies explored mothers' experiences from pregnancy to parenting older children (see table 5). Three studies specified one child being an infant/toddler (Cleveland, Bonugli & McGlothen, 2016; Silva, et al., 2012; Sorbo, Beveridge & Drapeau, 2009) with two studies having a broad age range from new-born to grown children (Secco, et al., 2014; Hardesty & Black, 1999). Haritavorn (2016) provided no information about children. The participants were predominately involved with substance misuse services and none of the services provided specific parenting interventions. Participants were all drug-users at varying degrees of recovery. Five studies were qualitative and one was mixed methodology with all studies using interviews to gather data. Participant numbers ranged from 1 to 30 with one case study included (Sorbo, Beveridge & Drapeau, 2009). The studies were conducted in a range of countries, Portugal, USA, Canada, Thailand and Puerto Rican women in Connecticut. This is important as being a mother and beliefs about mothering are influenced by society and culture. Any differences felt to be due to culture will be discussed in the themes.

#### **Results of synthesis**

Seven themes were identified through reciprocal translation (see table 6 and appendix 2.4 for full description of synthesis). Each theme will be described below. For consistency pseudo-names will be used to identify mothers. For the papers that used numbers pseudo-names were assigned and for the two papers that did not identify the mothers, unknown will be stated (Cleveland, Bonugli & McGlothen, 2016; Hardesty & Black, 1999).

Authors	Setting	<b>Research Aims</b>	Participants	Research methods
Haritavorn	Bangkok.	Examine the	30 mothers (20-47 years	Qualitative
(2016)	Thailand.	experience and	old). No specific	phenomenological
	Drop in	role that	information about children	approach. In-depth
	centres,	motherhood	provided.	interviews, participant
	methadone	plays in shaping	All injecting drug users –	observation.
	clinics, and	injecting drug	heroin drug of choice.	Thematic analysis to
	participant's	using mothers in	10 of the women were	identify themes.
	homes.	Thailand lives.	outreach workers.	
		(p.1168)		
Cleveland,	South-west	"What are the	15 mothers (22-40 years	Qualitative descriptive
Bonugli &	USA.	mothering	old). Mean number of	approach.
McClothen	Two	experiences of	children 3; youngest an	Semi-structured
(2016)	community	women with	infant (age not specified).	interviews.
	treatment	SUD (substance	All identified as Hispanic.	Thematic analysis to
	facilities,	use disorders)?"	All drug users (14 heroin -	identify themes.
	one offering	(p.120)	13 receiving MM1, 1	
Casas and		"Γ	cocaine - abstinent).	Mined montitution and
	Canada	Prom momens	12 Caucastan mothers (20-	mixed quantitative and
(2014)	Callaua. Methadone	what are their	children aged 3months - 20	methodology paper
(2014)	Maintenance	experiences of	vears (mean 5.9 years)	Qualitative approach
	Treatment	mothering and	Attendance at MMT for 3	used to capture mothers
	(MMT)	the mother-child	months.	perspectives. Semi-
	program	relationship		structured interviews.
	providing	during		Content and thematic
	community-	addiction,		analysis to identify
	based	MMT, and		themes.
	services.	recovery?"		
		(p.140)		
Silva and	Lisbon,	Main research	24 mothers (24-42 years	Qualitative approach.
colleagues	Portugal.	question:	old). 1-6 children with	Interview, memos,
(2012)	Maternity	"How is it to be	youngest child	observational data and
	and an	a drug-addicted	1-32months.	constant comparison
	Addiction	mother?"	Attending a supervised	method.
	I reatment	(p.360)	All consumed drugs	Grounded theory
	Centre		All consumed drugs	approach to analysis.
			(neroni/cocanie) and mothedone whilst	
			pregnant	
Sorbo	Western	Explore the	Case study – Caucasian	Case study qualitative
Beveridge	Canadian	participant's	mother mid-20s Three	approach
& Drapeau	city.	experience of	children (18months, 8	Three semi-structured
(2009)	Post	addiction	years and 9 years at time	interviews.
	discharge.	recovery and	of interview) – removed	Consensual Qualitative
	U	understanding	and returned to her care.	Research approach to
		of herself as a	Cocaine addiction, in	identifying domains
		mother. (p.70)	recovery.	then themes.
Hardesty &	Hartford,	Explore the	20 Latina mothers (19	Qualitative life history
Black	Connecticut.	mothering life	Puerto Rican, 1 Dominican	approach.
(1999)	Community-	and experiences	Republic; 23-48 years old).	Semi-structured
	based.	of addicted	All mothers except one	interviews.
		Puerto Kican	who miscarried, children	Grounded theory
		mothers. $(p.602)$	new-borns to grown	approach to analysis.
			specified)	
			Specificu). Crack-cocaina or horoin	
			addiction Varving stages	
			- active addiction to	
			recovery.	

 Table 5: Table of Characteristics from Studies in Synthesis

Table 6: Themes	identified	through	meta-ethnog	graphy	reciprocal	translation

Theme	Reciprocal	Studies
	Translation	
	Finding	
Unplanned pregnancy	3 out of 6	Cleveland, Bonugli & McGlothen (2016);
anxiety		Haritavorn (2016);
		Silva, et al. (2012);
Child as motivation	6 out of 6	Cleveland, Bonugli & McGlothen (2016);
		Hardesty & Black (1999);
		Haritavorn (2016);
		Secco, et al. (2014);
		Silva, et al. (2012);
		Sorbo, Beveridge & Drapeau (2009)
Ambivalence between	4 out of 6	Cleveland, Bonugli & McGlothen (2016);
hope of parenting and		Haritavorn (2016);
guilt of consequences		Silva, et al. (2012);
		Sorbo, Beveridge & Drapeau (2009)
Minimal parenting	3 out of 6	Hardesty & Black (1999);
		Silva, et al. (2012);
		Secco, et al. (2014);
Separation	6 out of 6	Cleveland, Bonugli & McGlothen (2016);
		Hardesty & Black (1999);
		Haritavorn (2016);
		Secco, et al. (2014);
		Silva, et al. (2012);
		Sorbo, Beveridge & Drapeau (2009)
Intervening factors	5 out of 6	Cleveland, Bonugli & McGlothen (2016);
		Haritavorn (2016);
		Secco, et al. (2014);
		Silva, et al. (2012);
		Sorbo, Beveridge & Drapeau (2009)
Redefining the	3 out of 6	Hardesty & Black (199);
maternal identity		Secco, et al. (2014);
		Sorbo, Beveridge & Drapeau (2009)

#### Unplanned pregnancy anxiety

Pregnancy was a main theme in three studies identifying that for most mothers their pregnancy was unplanned and experienced with shock and anxiety (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Silva, et al., 2012). The unplanned nature of pregnancies was often due to mothers' beliefs that they were unable to have children due to their drug use (Haritavorn, 2016; Silva, et al., 2012).

"I have never thought of being pregnant. My pregnancy was unintended. My periods had stopped since using drugs so I thought I was infertile. One day, the nurse at methadone suspected that I was pregnant. She asked me to have a pregnancy test and the result turned out positive. I was so shocked." (Naridee; Haritavorn, 2016, p.1172).

The unplanned nature of pregnancy meant it was often discovered late, resulting in less time for mothers to physically and psychologically prepare for motherhood (Cleveland, Bonugli & McGlothen, 2016; Silva, et al., 2012). Some women thought of aborting their pregnancy to avoid or delay motherhood (Silva, et al., 2012). Cleveland, Bonugli and McGlothen (2016) found pregnancy triggered traumatic memories of miscarriage, stillbirth and pre-term birth adding additional emotional distress.

"Immediately what came into my head was the fact that I had miscarried before." (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.112).

#### Child as motivation

Being motivated by their child was identified as a key concept across all the studies (see table 6) and was a main theme in 5/6 studies (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Secco, et al., 2014; Sorbo, Beveridge & Drapeau, 2009; Hardesty & Black, 1999). In all the studies mothers who misused substances were motivated by their pregnancy/child to change; either to keep their children or have them returned to their care. Mothers were not motivated to enter treatment for themselves, but were motivated to do so for their child (Cleveland, Bonugli & McGlothen, 2016; Secco et al., 2014 Silva, et al., 2012; Hardesty & Black, 1999). Some mothers' motivation to recover from substance misuse was linked to dreams of being a 'good' mother (Haritavorn, 2016).

"She is like the light in my life. When I look at her face, I want to be a maee thee dee (good mother)... She gave me a future which I never thought of. What I should do for her is quit using drugs..." (Parisa; Havitavorn, 2016, p.1173).

Mothers' perceived their pregnancy to be directing them away from addiction and they placed expectations on their child to aid their recovery (Cleveland, Bonugli & McGlothen, 2016; Silva et al., 2012).

"I think [my pregnancy] happened for a reason" (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.123).

Motivation is complex. Tina described her children as the "whole reason" (Sorbo, Beveridge & Drapeau, 2009, p.74) for recovering. The researchers noted Tina contradicted herself, as she was unsure if she would have recovered if her partner who misused substances had not completed suicide (Sorbo, Beveridge & Drapeau, 2009). Her motivation for her children possibly increased when the choice between her children and partner was taken from her.

#### Ambivalence between hope for parenting and guilt for consequences

This theme drew together concepts across four studies that identified the challenges of managing guilt and shame around substance misuse alongside motivation for parenting (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Silva, et al., 2012; Sorbo, Beveridge & Drapeau, 2009). One area of distress is substance use during pregnancy and the fear of the consequences for their child (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Silva, et al., 2012). Most mothers hoped to stop using substances during pregnancy; however, some were unable to maintain abstinence due to the severity of their addiction (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Silva, et al., 2012).

"I used drugs when I knew I was pregnant, sometimes I relapsed and I felt very scared and guilty for the consequences it could bring to my child." (Jane; Silva, et al., 2012, p.362).

Ambivalence between hope and despair can result in a cycle of guilt (Silva, et al., 2012). Some mothers coped with this using "normalisation" (Silva, et al., 2012, p.362) of their drug use; for example no other addicted mother would be able to abstain. However, the case study described maintaining abstinence during pregnancy through a "sense of obligation" (Sorbo, Beveridge & Drapeau, 2009; p.74) for her children.

"The only reason I did quit using was because I was pregnant not because I wanted

to." (Tina; Sorbo, Beveridge & Drapeau, 2009, p.74).

Mothers experience this ambivalence differently and the hope for children and fear of consequence may be motivating for some mothers.

Experiencing their new-borns in substance withdrawal also caused mothers distress (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016).

"I saw [my baby] shaking. It broke my heart seeing him going through those withdrawals" (Unknown; Cleveland, et al., 2016, p.123).

Being involved in caring for their infants' appeared to help mothers come to terms with the consequences and make amends for causing withdrawal (Cleveland, Bonugli & McGlothen, 2016).

"I needed him, and he needed me. I needed him because-I did something bad. I hurt him. If it wasn't for my drug use, my stupidity-he wouldn't be going through this. I put him through this and need to be there to help him because he needed my help. He's just an angel-a baby. I had to be there. I put him in that position and I-myself-had to help him-no one else." (Unknown; Cleveland, et al., 2016, p.124).

#### Minimal parenting

This theme was a main theme in three of the studies. Silva and colleagues (2012) identified a "functional (minimal) parenting" (p.262) theme, Secco and colleagues (2014) identified a subtheme of "diminished performed mothering" (p.143) and Hardesty and Black (1999) theme of "doing it all" (p.609).

Mothering is only part of the woman's role when misusing substances (Secco, et al., 2014; Silva, et al., 2012; Hardesty & Black, 1999). Hardesty and Black (1999) theme identified mothers "balancing two lines of work…habits as an addict and her life as a mother" (p.610). "Compartmentalising" (Hardesty & Black, 1999, p.610) their lives in this way means mothers can attempt to keep the home safe for mothering. The synthesis found mothers with substance misuse issues focused on meeting their children's physical needs (Secco, et al., 2014; Silva, et al., 2012; Hardesty & Black, 1999), for example one mother described how she would:

"...line up his clothes from Monday to Friday for school..." (Hannah; Secco, et al., 2014, p.144).

Mothers find it more challenging to meet children's emotional needs (Secco, et al., 2014; Silva, et al., 2012), for example:

"I get lost when she cries, I don't know what to do!" (Anne; Silva, et al., 2012, p.363).

However, the Puerto Rican mothers described meeting all their children's needs; physical and emotional needs, discipline, and preventing harm (Hardesty & Black, 1999). The

researchers stated "our participants preserved their identities by claiming to meet four requirements of motherhood" (Hardesty & Black, 1999, p.609). They suggested that maintaining a positive view of oneself as a mother protects against stigma and maintains social connections (Hardesty & Black, 1999).

Some mothers described their drug use as important in facilitating mothering (Silva, et al., 2012; Hardesty & Black, 1999). Minimum doses of drugs and controlled withdrawal meant mothers felt well enough to meet their children's basic needs and prevent harm (Silva, et al., 2012). Others claimed that a regular drug supply aided them in performing their mothering, for example getting out of bed (Hardesty & Black, 1999).

#### Separation

All the studies in the synthesis spoke of separation, either as fear of separation occurring (Cleveland, Bonugli & McGlothen, 2016) or physical separation, which was a main theme in three studies (Haritavorn, 2016; Secco, et al., 2014; Hardesty & Black, 1999). Two studies spoke of separation through family involvement (Havitavorn, 2016; Silva, et al., 2012). The case study reflected on her experiences of separation having successfully had her children returned to her care (Sorbo, Beveridge & Drapeau, 2009).

Mothers feared separation and had a strong desire to continue being a mother (Cleveland, Bonugli & McGlothen, 2016; Secco, et al., 2014).

"Keeping my children is my reason for staying clean..." (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.125).

However, relapse is a common part of substance misuse recovery. Mothers were not always aware describing "tunnel vision" (Hannah; Secco, et al., 2014, p.144) on their drug use and being "totally in denial" (Tina; Sorbo, Beveridge & Drapeau, 2009, p.74) of the harm they were causing their children. The balance changes with more time spent on drugs than mothering (Hardesty & Black, 1999).

"I just wanted to keep using. Worrying about getting it, I did not have time to think about my children." (Unknown; Hardesty & Black, 1999, p.612).

When mothers were no longer able to care for their children well enough or feared the impact of growing up "in the drug milieu" (Chanitnun; Haritavorn, 2016, p.1174), this often led to separation either by relinquishing care to relatives or child welfare services removing their child (Haritavorn, 2016; Secco, et al., 2014; Hardesty & Black, 1999). For some mothers, the criminal activities conducted to access money for drugs led to

separation due to prison time (Secco, et al., 2014). Separation was a painful and "horrible" (Jennifer; Secco, et al., 2014, p.144) for mothers, causing distress (Secco, et al., 2014; Hardesty & Black, 1999). It often triggered a worsening in substance use before hope of having their children returned motivated them to change (Hardesty & Black, 1999).

Culture plays an important role in understanding separation. For the Puerto Rican mothers living in Connecticut, giving voluntarily care to family members was not experienced as negatively as children's services removing their child (Hardesty & Black, 1999). In Latino culture it is commonplace for both the mother and grandmother to take the mothering role. Although voluntary separation was still painful the Latino mothers preferred this option, as it was perceived as their mother stepping into their role, which produced less "mother guilt" (Hardesty & Black, 1999, pp.613). Hardesty and Black (1999) felt children being cared for by family would be experienced with more guilt by Anglo mothers due to the lack of shared mothering in the culture.

In other cultures children living with family can result in control and punishment of mothers by families (Haritavorn, 2016; Silva, et al., 2012). In Silva and colleagues (2012) study, Portuguese mothers identified that the grandmother was often the primary caregiver (11/24) with difficulties such as "excessive control" (p.364) over mothers, which caused family conflict and prevented the mother from fully assuming the maternal role. Thai families also had huge influence over mothers and would punish their daughters with adoption of their children within the family (Haritavorn, 2016).

"My sister adopted my daughter when she was young. They, my family, thought I was not able to raise her and I did not deserve to be a mother because of my drug use. My daughter called me bpaa (aunt), but my sister maae (mother). My sister asked her to do so..." (Angkana; Haritavorn, 2016, p.1175).

Thus voluntary separation is positive for mothers in allowing access to their children but familial factors of control and punishment can make voluntary separation stressful and filled with conflict for mothers, depending on the culture.

#### **Intervening Factors – Social Support and Recovery Strategies**

The importance of social supports and recovery strategies was a main theme in four of the studies (Cleveland, Bonugli & McGlothen, 2016; Haritavorn, 2016; Secco, et al., 2014; Silva, et al., 2012). A fifth study also identified the importance of external supports in recovery (Sorbo, Beveridge & Drapeau, 2009). Social support for mothering was important for women to be able to maintain recovery and care for their children

(Haritavorn, 2016; Secco, et al., 2014; Silva, et al., 2012; Sorbo, Beveridge & Drapeau, 2009). As highlighted in the separation theme, family were often who the mothers called on for support (Haritavorn, 2016; Silva, et al., 2012). Grandmothers or social workers were supportive to mothers in their mothering role; however, this was often by reminding mothers of their fear of separation (Secco, et al., 2014).

It was important to mothers to have partners who were supportive during pregnancy and considered entering addiction treatment together (Silva, et al., 2012). For mothers who continue to use substances, partners who are happy to be fathers and providing emotional and/or monetary support are important for recovery (Silva, et al., 2012). However, when a partner continues to use substances while the mother is in recovery, this often results in mothers making the decision to end the relationship (Cleveland, Bonugli & McGlothen, 2016; Silva, et al., 2012).

"...I had to [end the relationship]; I had to. Hopefully one day he'll see me and our son doing great and wanna come along and be in our lives. It's a grieving process because it's like losing a best friend in death. He's suffering, and I know how he feels..." (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.125).

Mothers would also seek to change their environment and social supports to aid recovery (Cleveland, Bonugli & McGlothen, 2016). When they had the finances woman often moved home explaining;

"I needed to get away from that neighbourhood and the people." (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.125).

If they were unable to move, mothers drew upon their recovery strategies, such as learning about their triggers for substance use (Cleveland, Bonugli & McGlothen, 2016).

Mothers highlighted the importance of professionals who understand and are supportive of them as mothers (Silva, et al., 2012). However, mothers often felt poorly treated by professionals increasing their social stigma and risk of relapse (Cleveland, Bonugli & McGlothen, 2016; Silva, et al., 2012). Several mothers spoke of hearing nurses in the baby unit using stigmatising labels such as "that junkie mom" (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.124), which often led to them avoiding staff or relapsing. Mothers spoke of understanding why child protection services were involved but felt "…It's an embarrassment to me…" (Unknown; Cleveland, Bonugli & McGlothen, 2016, p.125) and found their involvement intrusive.

#### **Redefining the Maternal Identity**

The synthesis identified maternal identity as a main theme in two of the studies (Secco, et al., 2014; Hardesty & Black, 1999) and that the case study spoke of identity in its motherhood subthemes of "interrupted identity development" and "who I am, what I am becoming?" (Sorbo, Beveridge & Drapeau, 2009, p.73). During recovery from substance misuse mothers try to recover their maternal identity (Secco, et al., 2014; Sorbo, Beveridge & Drapeau, 2009; Hardesty & Black, 1999) as they have a strong desire to have their children in their care (Sorbo, Beveridge & Drapeau, 2009; Hardesty & Black, 1999) as they have a strong desire to have their children in their care (Sorbo, Beveridge & Drapeau, 2009; Hardesty & Black, 1999). Mothers focus shifts from drugs to their children, enjoying spending more time with them and developing an identity as a mother (Secco, et al., 2014; Sorbo, Beveridge & Drapeau, 2009).

"... I really like that about myself now that I want to play with my kids and be with them." (Tina; Sorbo, Beveridge & Drapeau, 2009, p.73).

Secco and colleagues (2014) subthemes of "positive performed mothering" and "positive mother-child relationship" (p.144) highlighted mothers being able to be emotionally and physically available to their child. In the case study, Tina spoke of characteristics such as "dependability, reliability and strength" (Sorbo, Beveridge & Drapeau, 2009, p.73) that helped her develop an identity as a good parent. Restored maternal identity brings positive feelings for mothers;

"Oh it's awesome, it's wonderful...I actually have a normal relationship with my children. I feel like a mom instead of, you know, just like I used to." (Susan; Secco, et al., 2014, p.144).

"Recovering the mother identity" (Hardesty & Black, 1999, p.614) involves mothers coming to terms with their past deficits as a mother and understanding their child's experiences of these, which is a process full of guilt. Successful maternal identity development also involved the child's willingness to rebuild the relationship and trust in the mother's new identity (Secco, et al., 2014; Hardesty & Black, 1999).

"...many times I spoke ill to him and he answered me in the same way. He was mad at me. He probably noticed my problem and didn't say anything to me. I offended him a lot. Not long ago I asked him for his forgiveness." (Unknown, Hardesty & Black, 1999, p.615).

Not all children are able to engage with rebuilding a relationship with their mother (Secco, et al., 2014; Hardesty & Black, 1999). In Secco and colleagues research (2014), two

mothers had "the pattern of continued diminished mothering and negative mother-child relationship" (p.145).

"My daughter always yells and screams at me that I'm a drug addict, always. My daughter can't get over it... and it's not true, I don't do drugs anymore... (crying)..." (Shannon; Secco, et al., 2014, p.145).

Mothers can enter a cycle where their expectations of reconnecting with their children are high and when these are not met they feel a sense of failure, which can lead to relapse (Hardesty & Black, 1999). Having strength and commitment for their children and embracing the possibility of reconnecting with them makes recovery of the mothering role and identity possible (Sorbo, Beveridge & Drapeau, 2009; Hardesty & Black, 1999).

#### DISCUSSION

This systematic review looked at women who misuse substances and their experiences of being a mother. The synthesis identified seven themes; (1) unplanned pregnancy anxiety, (2) child as motivation, (3) ambivalence between hope for parenting and guilt for consequences, (4) minimal parenting, (5) separation, (6) intervening factors–social support and recovery strategies, and (7) redefining the maternal identity.

The findings suggest that pregnancy is frequently unplanned and experienced with anxiety. Pregnancy is often discovered late, which impacts on the time to prepare for becoming a mother. However, pregnancy/children were also experienced with hope and motivation to change. Many mothers felt ambivalence between the desire to change and guilt about the impact of their substance use. This cycle of guilt passes, using normalisation of their relapses and possibly by supporting their infant through withdrawal. Mercer's (2004) becoming a mother theory highlights the importance of pregnancy as a time for commitment, preparation, and attachment. The unplanned nature of pregnancy, and cooccurring role as an addict or recovering addict, likely makes this process more challenging.

When mothers are using substances they meet the basic physical needs of their children. Previous qualitative studies have also reported that mothers identify as being 'good mothers' when they meet their children's basic needs (Brown, 2006; Baker & Carson, 1999). These studies also support the findings in showing that mothers recognise their deficits in emotional support (Brown, 2006; Baker & Carson, 1999). The balance of drug use and mothering is not maintainable and separation is common; either voluntary or by children's services. Voluntary separation can also occur as a preventative decision when mothers notice that their parenting is not good enough and they relinquish care to relatives. Culture and family systems can affect how mothers experience their relatives caring for their children. Separation is a painful experience for mothers and can initially increase substance misuse. Previous qualitative research also spoke of the suffering that mothers experienced through separation experiencing a numb disconnection from their feelings and using substances to cope (Kenny, Barrington & Green, 2015; Memarnia, et al., 2015). However, many mothers showed a desire to keep their children or have them returned to their care, which motivated them to re-engage with recovery. Previous qualitative research, focusing on experiences of separation of mothers who use drugs, also identified that the hope of reunification helped mothers manage separation (Kenny, Barrington & Green, 2015).

Positive social supports were important in helping mothers recover and develop a good sense of maternal identity. Stigma from professionals was challenging for mothers, and reduced their engagement with services, and risked relapse. Memarnia and colleagues (2015) also identified that during separation mothers found services unsupportive; resulting in feeling powerless, angry, and isolated. Maternal identity is complex for these mothers. It involves recovering an identity as a mother that they had not completely fulfilled while misusing substances, whilst also redefining their maternal identity as they develop their sense of identity as a mother and addict in recovery. A previous qualitative study about mother's experiences of separation identified that that mothers need to build a new identity that is different to their past identity when they were a mother and an addict (Memarnia, et al., 2015). The mothers feel uncertain about their maternal identity from other people's perspective when they do not have their children in their care making the recovery and redefining of their maternal identity even more complex (Memarnia, et al., 2015). Mothers need to be able to tolerate and process the complex emotions generated by the possibility of not being able to reconnect with their children. Memarnia and colleagues (2015) identified how challenging this ambiguous loss is for mothers managing the complex emotions evoked by their children being alive but not in their care.

#### Limitations

All the studies included in the synthesis focus on drug misuse. The study excluded at quality rating was with mothers who misused alcohol (Brudenell, 1996). Therefore, more good quality research is needed with mothers who misuse alcohol to identify their specific

needs. With alcohol being legal, it is possible that this population are more hidden and thus harder to access and research.

A number of the studies lacked reflexivity at quality rating. This is a limitation as it is possible that the lack of reflection on the impact of the researchers background and perspectives on their research could have biased their findings. The researcher has tried to be reflective about the impact of her different background to those researched throughout this synthesis to reduce the risk of interpretation bias. However, due to the nature of qualitative research the findings of this study are unique.

#### Implications

Understanding mother's experiences can help clinicians reduce social stigma by employing empathy and reducing the shame and isolation that mothers feel about being a mother who misuses substances. Identifying the experiences of mothers allows clinicians to identify where mothers are in their process of mothering and recovery. This allows clinicians to draw more effectively on evidenced-based approaches such as identifying the stage of change (Prochaska & DiClemente, 1982), and using motivational interviewing to move towards recovery (Miller & Rollnick, 2012). This review identified that mothers are motivated to change for their children and changing for their children can be more powerful than changing for themselves, which could be beneficial to clinicians in utilising motivational interviewing more effectively to move towards addiction recovery. In Scotland, the Matrix (NHS Education for Scotland, 2015) is a guide to utilising evidence-based psychological therapies. It highlights that the most complex cases requires highly skilled practitioners to draw on multiple therapeutic models to develop a shared formulation. The themes of this review inform practitioner's formulations and help consider the impact of guilt, separation and identity in recovery.

Parental substance misuse use can have a significant impact on a child's wellbeing with treatment of parents having a positive impact on a child (Advisory Council on the Misuse of Drugs, 2011). Improving engagement in services with integrated addiction and parenting interventions have been found to have positive outcomes; for mothers, but also for child wellbeing (Sword, et al., 2009). Focusing on the needs of children could also help reduce the risk of intergenerational cycles of child removal and improve outcomes for children, such as reduce risk of criminal justice involvement and improve mental health outcomes for children leaving care.

#### CONCLUSIONS

The findings of this review show the processes by which woman experience being a mother whilst misusing substances. From the anxiety of an unplanned pregnancy they feel motivation to change for their child as well as despair for the consequences of their substance use. Pregnancy can initiate recovery but relapse is common and minimal parenting on substances can occur. When the priority of substance use wins over mothering, separation can occur. Although this is devastating, and can initially increase substance use, it can ultimately increase a mother's motivation to recover. Rebuilding a maternal identity is fraught with difficulties and requires commitment, time, and trust from mothers and children. This can be challenging for mothers to accept and there is a risk of relapse. Services need to be well placed to identify where mothers are in these processes and to reduce stigma and support motivation for children and recovery. This review has focused on mothers' experiences with the hope that by improving understanding of mothers we may be able to break the cycle of repeat pregnancies and improve outcomes for children as well as mothers.

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#### **CHAPTER TWO**

## Identifying grief in parents who have had children removed from their care within Addictions Services: A pilot study.

#### **Ruth Anderson BSc (Hons)**

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

Prepared in accordance with Addiction Journal guidance for publication (see appendix 1.1).

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Word count - 6955

**Plain English Summary:** Identifying grief in parents who have had children removed from their care within Addictions Services: A pilot study.

**Background**: Grief occurs following a loss and it takes time to make sense of the loss. Loss is wide-ranging from death of a loved one to loss of anything meaningful for example loss of a job. Previous research interviewed mothers about their experience of having their child removed from their care by social services. These studies have suggested that mothers experience the loss of their child with a grief reaction. However, parents' loss following removal of a child has not been researched in a purely addictions population or with a grief questionnaire.

**Aims and Questions:** This is a pilot study, which means it is trying out a grief questionnaire with an addictions population on a small scale to inform bigger future studies. The study aimed to identify that parents were experiencing grief following the removal of their child. It also aimed to look at how the parent and bereaved groups were different and how they were the same.

**Methods:** Participants were from a community addictions service. There were three groups. One group was parents who had a child removed from their care by social services. The second group consisted of bereaved individuals who were upset by the death of a loved one. The third group was a control group who were no longer upset by the death of a loved one. Recruitment was at addictions clinics and by Clinical Psychologists from their cases. Participants completed a grief questionnaire about thoughts that make grief more challenging, a mental health questionnaire, and a substance misuse information sheet. The grief questionnaire for parents was adapted. Participants identified themselves as a parent or bereaved individual and identified if they were still upset by their loss using a description of distress.

The three groups were compared on their total scores on the grief questionnaire to test if parents and bereaved individuals experience grief when compared to the control group.

**Main Findings:** Twenty-nine participants took part in the study. Compared to the control group, the parents and bereaved individuals were experiencing grief as measured by the grief thoughts questionnaire. The parents had particular difficulty with negative thoughts about self, others and self-blame compared to the bereaved group. The study did not have enough participants to test how the parents and the bereaved groups were the same.

**Conclusions:** This pilot study was helpful in showing the benefits of using the grief questionnaire in addictions services and with parents. A bigger future study should consider more creative ways to recruit individuals as this was challenging for this pilot. For example use of experts by experience to assist with engagement. This pilot study highlights the importance of this area for future studies as the participants of this study had more grief thoughts than the general grieving population on the grief questionnaire. This shows that grief an important issue and future studies should explore this further.

Word Count - 498

#### ABSTRACT

**Background:** Grief is an emotional reaction to a loss with negative grief cognitions making grief more complicated to process. Qualitative research has identified factors that may make the removal of a child challenging for birthparents including; blame of self or others, challenges to identity and perception of support from others.

**Aims:** This study piloted the use of a grief questionnaire with an addictions population. It aimed to identify if birthparents experience grief following the removal of their child. The study aimed to identify the differences and similarities in grief between birthparents and bereaved individuals.

**Design:** A cross-sectional design compared three groups from an addictions service; group one birthparents who have had a child removed from their care, group two a bereavement group with on-going distress and group three an addictions population control group who are no longer distressed by a past bereavement.

Setting: Participants were 29 community addiction team patients.

**Measurements:** A negative grief cognitions questionnaire (Grief Cognitions Questionnaire), a measure of anxiety and depression (Hospital Anxiety and Depression Scale) and substance use were conducted.

**Findings:** A three-group nonparametric analysis identified that the birthparents and bereaved groups had significantly more negative grief cognitions compared to the control group with large effect sizes. Birthparents reported slightly more negative grief cognitions that the bereaved group with a small effect size. Further nonparametric statistical testing identified that birthparents experience significantly more grief cognitions about self-blame than bereaved individuals with a large effect size. Birthparents reported slightly more negative grief cognitions about self-blame than bereaved individuals with a large effect size.

**Conclusions:** Birthparents and bereaved individuals both experience grief as measured by the grief questionnaire, with birthparents experiencing more negative cognitions around self-blame, self and others. Suggestions are made about improving accessibility and feasibility of recruitment and design for future studies.

Keywords: substance misuse, child removal, parent, grief

#### **INTRODUCTION**

#### The context of child removal

In Scotland around 150,000 children, which is likely an underestimate due to a lack of good quality evidence, are affected by parental substance misuse (The Scottish Executive, 2006). Substance misuse has a negative impact on parenting ability and increases the risk of all types of abuse (The Scottish Executive, 2006). Consequently, separation from their children can occur. Some mothers voluntarily separate from their child, involving relatives in childcare (Haritavorn, 2016; Silva, et al., 2012; Hardesty & Black, 1999). However not all mothers recognise the impact of their substance misuse on their child, which can result in removal of their children by social services (Powis, et al., 2000). One qualitative study suggests that mothers experience voluntary and social services separation differently (Hardesty & Black, 1999). Although voluntary separation can cause family conflict (Haritavorn, 2016; Silva, et al., 2012), for Puerto Rican mothers service removal can cause more guilt, fear of the impact on their child, and challenges to maternal identity (Hardesty & Black, 1999). However, Memarnia and colleagues (2015) noted that in the UK there is a lack of research on birthparents experiences of child removal by social services with a need for increased research of their unique experiences.

#### Impact of child removal on birthparents

Birthmother's who misuse substances experience the removal of their children from their care as highly distressing (Secco, et al., 2014; Hardesty & Black, 1999). Schofield and colleagues (2011) combined data from three qualitative studies of birthparents experiences of child removal and identified that birthparents experience grief. Grief results in a loss reaction and a range of emotions and signs (Corr, 2002). A review of the literature regarding complicated grief identified five studies that indicate that many people respond to a death with an acute grief response that reduces over time (Shear, Simon & Wall, 2011). However, they identified a further five studies that indicate that some individuals experience more longstanding intense symptoms termed complicated grief (Shear, Simon & Wall, 2011). Furr, Johnson and Goodall (2015) identified the pervasiveness of loss that individuals who misuse substances experience, prior, during and in recovery from substance misuse. Losses include death, loss of relationships, loss of time, and loss of parts of self; such as confidence (Furr, Johnson & Goodall, 2015). Their study recommends grief work during recovery; however, this involves tolerating intense emotions, which they have avoided through substance misuse (Furr Johnson & Goodall, 2015). Therefore, birthparents likely experience complicated grief following the removal of their child, which is more challenging to process due to their substance misuse.

#### **Impact on emotions**

Research with birthparents has identified specific emotions that are challenging when processing their experiences. One study with birthmothers who relinquished their children for adoption identified a significant association between high emotions of shame and guilt and complicated grief (De Simone, 1996). This result suggests that guilt and shame are associated with more difficulty with grief (De Simone, 1996). Qualitative research with birthparents with children in foster care identified feelings of guilt, blame and responsibility for their children being in the care system (Schofield, et al., 2011). However, some birthparents felt they were not responsible for the removal of their child and described externalising their blame with feelings of anger towards services or their partner (Schofield, et al., 2011). Memarnia and colleagues (2015) qualitative research also identified anger towards services from birthmothers who had their children removed, as they felt unsupported to improve their circumstances. These studies are challenging to interpret as research covers relinquishing care as well as child removal by services. Also, the populations were selected for their experience of child removal not substance misuse. As Schofield and colleagues (2011) described about their sample, there are multiple reasons that children are removed, such as; mental health, violence, and substance misuse. Therefore, further research exploring blame with birthparents within the substance misuse population alone is needed to identify their experience of blame towards themselves and others.

#### Impact of perceived social supports

The role of others is further complicated by how society responds to the removal of the child. Doka (1989) developed the term disenfranchised grief; that is a loss that is not socially validated, or acknowledged, or mourned publicly. When a loss is not recognised, it can result in less access to supports and increase the complexity of the emotional response (Doka, 2002). Removal of a child into care has been identified theoretically in qualitative studies as disenfranchised grief (Memarnia, et al., 2015; Schofield, et al., 2011). Further research is needed to explore how birthparents with substance misuse problems perceive support from others following the removal of their child.

#### Impact on sense of self

Qualitative studies have also identified the significant impact that removal of a child has on the identity of birthmothers who misuse substances (Secco, et al., 2014; Hardesty & Black, 1999). Studies describe birthmothers feeling lost or different about their identity and questioning how others might perceive them (Mermarnia, et al., 2015; Schofield, et al.,
2011; Hardesty & Black, 1999). Ongoing contact and the ambiguous nature of the loss, with the child still being alive, can make managing identity and processing the separation more challenging (Mermarnia, et al., 2015). However, quantitative research has not explored the impact of removal of child on birthparents beliefs about themselves.

# Limitations of current literature

The current literature suggests that birthparents experience the removal of their child by social services with difficult emotions and a negative impact on their sense of self. Their loss is further complicated by the social context and their beliefs about others' perceptions of them as parents. This is also in the context of their substance misuse, which likely limits their ability to process their intense emotions. However, these studies are predominately qualitative, rarely used formal measures, often are not purely substance misuse populations, often did not include fathers, and did not compare this loss to other grief reactions.

#### Aims and research questions

Therefore, the project aims to pilot the use of a quantitative grief questionnaire with a substance misuse population. It also poses the following questions:

- Do birthparents that have had a child removed from their care and bereaved individuals within addictions services experience grief compared to a general addictions population?
- Are there differences in birthparents experiences of grief compared to bereaved individuals? Do birthparents have more difficulty with blame, self, and a perceived lack of support from others?
- Are there similarities in birthparents' experience of grief compared to that of bereaved individuals?

## METHODOLOGY

## Design

A cross-sectional design was used to compare grief cognitions between three addiction service groups. The groups are: (i) parents who have had a child removed from their care by social services, (ii) bereavement/death of someone close to them that causes distress, and (iii) control group with bereavement/death of someone close to them that has been processed and no longer causes distress. A control group was included to provide a baseline measure for the substance misuse population on the grief cognitions questionnaire. The control group accounts for the role of substance misuse and the level of grief. The control group participants experienced a death of someone close to them over 12 months ago, guided by literature identifying that a normal grief reaction is processed in 6-12months (Bryant, 2012).

Consultation with the Robertson Biostatistics Centre (University of Glasgow) confirmed that if there are no similar studies it is a pilot study. A pilot study is a small version of a final study (Arain et al., 2010). This study is piloting a quantitative grief questionnaire, which is new to this population, and pilots the three-group design that would be used in a larger study. There are also some feasibility elements to this study as guided by Arain and colleagues (2010) description of a feasibility study. Therefore, this study aims to consider the usefulness of the questionnaire as an outcome measure, feasibility of recruitment approach and methods, and collect data to inform future sample size calculations. Exploratory hypothesis testing will be conducted to inform understanding of the usefulness of the questionnaire as an outcome measure. Advice from the literature about a sample size for a pilot study is varied with one researcher arguing for a rule of thumb of 12 per group (Julious, 2005) and another recommending a minimum of 25 per group for considering instrumentation (Hertzog, 2008). Therefore, the study aimed to recruit 25 participants per group. A recent audit by the field supervisor identified that of the 3000 patients in the North West Community Addictions Team (NW CAT), 26% have bereavement issues and 19% have had a child removed from their care. It was estimated that 10-40 patients attend per half-day clinic. Thus it was felt that approaching 12-15 participants per month over 5-6months would be feasible.

## Ethics

NHS Research and Ethics Committee (REC), NHS Lanarkshire Research and Development (R&D) as sponsor and NHS Greater Glasgow and Clyde R&D as host health board granted approval for the project (see appendix 3.1).

## Recruitment

The researchers attended a women's recovery group in February 2017 to seek service user feedback and pilot the questionnaires. Recruitment took place from March to early June 2017, following the approved protocol (see appendix 3.2). There were two approaches to recruitment: the community addiction team clinics and Addiction Psychological Therapies Service. This aimed to improve the efficiency of recruitment in the timescale recognising the challenges of recruiting this population for research. The addiction team clinicians

independently disseminated the information sheet (see appendix 3.3), to make potential participants aware of the project before attending the clinic. Posters placed in the waiting room identified when the researchers would be present at the clinic (see appendix 3.4). When there was space for private rooms to be utilised, clinicians introduced the researcher to interested patients. When there was no private room available the researcher was present in the waiting room and identified to patients by staff on their arrival. This allowed potential participants to choose to approach the researcher. The Clinical Psychologists independently recruited participants from their caseloads.

#### **Participants**

The participants were patients of the NW CAT in NHS Greater Glasgow and Clyde and patients of the Addictions Psychological Therapies Service. Participants self-identified as being, either a birthparent who had a child removed from their care, or having experienced the bereavement/death of someone close to them. The bereavement group reported on-going distress following their loss and the control group reported no longer feeling distressed. Participants had clinically significant problems with substance misuse as defined by the International Statistical Classification of Diseases and Related Health Problems 10<sup>th</sup> Revision (World Health Organisation, 2016). All participants were over 18 years old and had adequate literacy skills. Participants were excluded if they were highly intoxicated or highly distressed.

#### Measures

Demographic information was gathered to confirm group allocation (see appendix 3.5). It asked if participants had any children removed, if so how many, and if the participant is distressed by the removal of their child. It also asked if they have experienced bereavement/death of someone close to them, how long ago it was and if they are distressed. A written definition of distress was provided to support self-diagnosis of on-going distress (yes/no).

The Grief Cognitions Questionnaire (GCQ; Boelen, van den Bout & van den Hout, 2003) was chosen as a measure as it focuses on the negative cognitions that make processing grief more challenging. A higher score indicates more difficulties with negative cognitions that make grief challenging. The total score comprises of nine subtests covering areas related to complex grief; self, world, life, future, self-blame, others, appropriateness, cherished grief, and threatening interpretation of grief. The GCQ has not been used with a substance misuse population or in connection with loss of children through removal. The

main author was contacted and permission given to use the questionnaire and create an adapted version for birthparents. The GCQ can be personalised with the person's name. Due to the research team not knowing the participants, they were made generic with "death of loved one" or "removal of child" inserted (see appendix 3.6). The psychometric properties of the GCQ have been assessed through online research, recruiting bereaved individuals from the general population with factor analysis indicating that the questions load onto the nine factors and there was adequate internal consistency with Cronbach's alpha 0.81- 0.95 for all subtests and 0.96 for the total score (Boelen & Lensvelt-Mulders, 2005). Further testing of internal consistency was undertaken as the measure was new to this population and adapted for birthparents. Internal consistency was tested using Cronbach's alpha with good internal consistency around 0.8 or above (Field, 2005).

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used as a measure of mental health factors across the groups (see appendix 3.7). It consists of 14 questions split into 2 subtests of anxiety and depression. A higher score indicates greater difficulties, with a score of 8 or above on a subtest indicating clinical problems. A review of the literature for use of the HADS with an alcohol dependent population concluded it is a suitable screening measure for mood and anxiety with adequate overall internal consistency with Cronbach's alpha over 0.7 (McPherson & Martin, 2011).

Information about substance use was gathered to identify current and historical substance use and any current replacement regimes (see appendix 3.8). The information was gathered to inform our understanding of these variables between our groups.

#### Procedure

After reading the information sheet, the researcher or Clinical Psychologist, sought written informed consent (see appendix 3.9). Consent included sharing any clinical concerns from the questionnaires with their clinician. Questionnaire packs were completed in the presence of a worker to provide support if required. There were two versions of the questionnaire packs, a birthparent version with the adapted GCQ and bereavement with the standard GCQ. Participants were presented with two envelopes labelled parent and bereavement, and asked to select the envelope relevant to them. Birthparents who were also distressed by bereavement completed the questionnaires for what they felt was their most significant issue. The worker enquired as to how participants were feeling following the completion of the questionnaires and provided them with a support services information sheet (see appendix 3.10).

# RESULTS

# **Demographic Information, Mental Health and Substance Use**

Twenty-nine participants were recruited; 9 birthparents, 15 bereaved, and 5 control group participants. One participant was removed from the birthparent group resulting in a final sample size of 28 (see table 1). The participant self-identified as a birthparent who had a child removed from their care; however, their partner was preventing access. The researchers concluded this is a different experience. This was also evident in the participant being an outlier on the core measure of self-blame on the GCQ.

	Parents	Bereavement	Control
	( <b>n=8</b> )	(n=15)	(n=5)
Gender:			
Female	5 (62.5%)	6 (40%)	3 (60%)
Male	3 (37.5%)	9 (60%)	2 (40%)
Self-rated distress:			
Yes	7 (87.5%)	15 (100%)	0 (0%)
No	1 (12.5%)	0 (0%)	5 (100%)
Historical substance use:			
Alcohol	0 (0%)	0 (0%)	1 (20%)
Drugs	1 (12.5%)	3 (20%)	1 (20%)
Poly-drugs	3 (37.5%)	10 (66.7%)	1 (20%)
Poly-substance (Alcohol & Drugs)	3 (37.5%)	2 (13.3%)	1 (20%)
Prescription drugs	1 (12.5%)	0 (0%)	0 (0%)
Missing data	0 (0%)	0 (0%)	1 (20%)
Current substance use:			
Abstinent	4 (50%)	3 (20%)	3 (60%)
Alcohol (occasional use)	1 (12.5%)	3 (20%)	0 (0%)
Drugs	2 (25%)	5 (33.3%)	1 (20%)
Poly-drug	0 (0%)	3 (20%)	0 (0%)
Poly-substance (Alcohol & Drugs)	1 (12.5%)	1 (6.7%)	1 (20%)
Replacement regime:			
Yes	8 (100%)	13 (86.7%)	3 (60%)
No	0 (0%)	2 (13.3%)	2 (40%)

**Table 1:** *Description of study participants (n=28)* 

Birthparents reported an average of two children removed from their care (mean=1.75, range=1 – 4). Two birthparents reported distress through bereavement; however, chose to complete the questionnaires as birthparents as they identified this as their most significant issue. One of the birthparents rated themselves as no longer being distressed by the removal of their child. Their experience on the measures was similar to the rest of the birthparent group therefore they were included in the sample.

The bereavement group reported an average of 10years 3months since their bereavement (range=4months – 31years 4months) and the control group reported an average of 19years 7months since their bereavement (range=1year 6months – 32years). The sample consists of equal numbers of males and females (14; 50%); however, there was variation across the groups with more females in the parent group (5; 62.5%) and males in the bereavement group (9; 60%; see table 1). Participants were predominately a drug misuse population.

Participants across the groups had difficulty with anxiety and depression (see table 2). The average scores for all groups fell above the clinical cut off outlined by the author (Zigmond & Snaith, 1983).

**Table 2:** Descriptive statistics of the Hospital Anxiety and Depression Scale (HADS) and
 clinical ranges outlined by the author

	Parents	Bereavement	Control
	( <b>n=8</b> )	(n=15)	(n=5)
HADS – Anxiety			
Median (Interquartile range)	13.50 (7)	16.00 (6)	15.00 (5)
Range (min-max)	18 (0-18)	16 (5-21)	6 (14-20)
Clinical range (base on median)	moderate	severe	severe
HADS – Depression			
Median (Interquartile range)	12.50 (12)	13.00 (6)	11 (3.7)
Range (min-max)	16 (1-17)	11 (7-18)	9 (6-15)
Clinical range (base on median)	moderate	moderate	moderate

## Piloting a grief questionnaire in an addictions population

All recruited participants successfully completed the questionnaire packs. Cronbach's alpha indicates good internal consistency for the majority of the subtests for the adapted birthparent GCQ (7/10) and bereaved group GCQ (6/10; see table 3). Internal consistency was low for the control group (2/10; see table 3).

	Number of items	Full sample GCQ (n=28)	Adapted GCQ for Parents (n=8)	Bereaved group GCQ (n=15)	Addictions control group GCQ (n=5)
Total	38	0.97	0.97	0.93	0.82
Self	6	0.91	0.92	0.88	0.46*
World	4	0.82	0.77	0.81	0.64*
Life	4	0.94	0.93	0.92	0.73*
Future	5	0.88	0.95	0.81	0.43*
Self-Blame	5	0.89	0.70*	0.75	0.94
Others	3	0.62*	0.64*	0.61*	0.34*
Appropriateness	4	0.78	0.68*	0.58*	0.68*
Cherished grief	3	0.69*	0.89	0.44*	0.66*
Threatening	4	0.86	0.80	0.71*	0.54*
interpretation of grief					

**Table 3:** Number of items and internal consistency (Cronbach alpha) on GCQ and
 Adapted GCQ

\* internal consistency inadequate (below 0.8)

The samples scores were compared to normative data presented by Boelen and Lesvelt-Mulders (2005). The normative data was collected to assess the psychometric properties of the GCQ. Participants were recruited from a grief website and all completed the questionnaire online. The final sample consisted of 531 participants over the age of 18 years old who had all experienced a death of a significant other (e.g. parent, spouse, sibling) in the past 10 years and were grieving. Compared with the data from the original study with a grieving population completing the GCQ in paper form, there was a slight but not significant difference in total score (mean=50.33, SD=37.45; Boelen, van den Bout & van den Hout, 2003). At a subtest level, those completing the electronic forms score

significantly higher than those completing the paper copies in the appropriateness of grief and threatened interpretation of grief subtests (Boelen & Lesvelt-Mulders, 2005).

The birthparents and bereaved individuals from this study have much higher scores compared to Boelen and Lesvelt-Mulders (2005) normative data for a grieving general population, meaning greater difficulty with grief cognitions (see table 4). It is also of note that the addictions control group scored similarly to the sample on the others and cherished grief subtests (see table 4).

	GCQ Normative Data from a Bereavement Sample (n=531)	GCQ with Addictions Control Group (n=5)	GCQ with Bereaved Addictions Group (n=15)	Adapted GCQ for Birthparents Addiction Group (n=8)
GCQ Subtests				
Total	53.70 (41.05)	31.60 (17.30)	104.67 (33.03)	121.75 (48.96)
Self	7.25 (7.69)	3.60 (3.29)	16.73 (7.63)	20.88 (8.95)
World	5.85 (5.84)	3.60 (3.39)	10.60 (4.66)	10.75 (6.39)
Life	5.35 (6.11)	1.00 (1.73)	10.87 (6.05)	10.38 (8.43)
Future	7.72 (7.13)	6.00 (4.74)	15.33 (5.94)	14.00 (10.00)
Self-Blame	5.37 (6.40)	2.80 (6.26)	13.00 (6.58)	21.75 (4.13)
Others	5.51 (4.93)	5.60 (3.58)	7.53 (3.46)	10.63 (3.62)
Appropriateness	5.01 (4.93)	1.60 (2.51)	11.00 (4.24)	11.25 (5.92)
Cherished Grief	3.88 (4.26)	3.60 (2.97)	6.47 (3.09)	7.63 (5.85)
Threatened Interpretation	7.75 (6.36)	1.80 (2.05)	13.13 (4.54)	14.25 (5.31)

**Table 4**: Birthparents and bereaved addictions groups GCQ mean (standard deviation)scores compared to the GCQ normative data (Boelen & Lensvelt-Mulders, 2005, p. 299)

# Do birthparents that have had a child removed from their care and bereaved individuals within addictions services experience grief compared to a general addictions population?

The descriptive statistics were explored for all three groups on the GCO (see table 5). The statistical analysis approach was exploratory with effect sizes calculated for all tests as it accounts for sample size. A three-group independent sample analysis comparing the GCQ total score across the addictions groups was conducted. Tests of normality and homogeneity of variance concluded that a non-parametric (Kruskal-Wallis) test was most appropriate. A Kruskal-Wallis test revealed a statistically significant difference in the total grief cognitions score across the three groups (n=28, H(2)=12.28, p=0.002). Mann-Whitney U testing was used to follow up this finding with effect sizes calculated for all tests conducted. Cohen's (1988) effect sizes are that small is r=0.1, medium is r=0.3, and large is r=0.5. The birthparents (median=134.50) reported significantly more grief cognitions compared to the control group (median=38.00) with a large effect size (U=0.00, z=-2.93, p=0.002, r=-0.81). The bereaved participants (median=93.00) also reported significantly more grief cognitions compared to the control group (median=38.00) with a large effect size (U=0.00, z=-3.27, p=0.000, r=-0.73). The birthparents (median=134.50) reported slightly more grief cognitions than the bereaved participants (median=93.00) with a small effect size (U=48.50, z=-0.74, p=0.466, r=-0.15). Therefore birthparents and bereaved groups reported more grief cognitions than the control group with significant findings and large effect sizes, with birthparents having slightly more grief cognitions than the bereaved group with a small effect size (see Figure 1).

# Figure 1: Boxplot of GCQ total scores



GCQ Subtest (Max score)	Adapted GCQ Parents (n=8)	GCQ Bereavement (n=15)	GCQ Control (n=5)	
Total (190)				
Median (Interquartile range)	134.50 (97)	93.00 (48)	38.00 (27)	
Range (min-max)	129 (55-184)	96 (62-158)	43 (2-45)	
Self (30)				
Median (Interquartile range)	23.00 (16)	16.00 (12)	3.00 (5)	
Range (min-max)	25 (5-30)	23 (7-30)	9 (0-9)	
World (20)				
Median (Interquartile range)	9.00 (13)	9.00 (7)	3.00 (5)	
Range (min-max)	16 (4-20)	14 (5-19)	9 (0-9)	
Life (20)				
Median (Interquartile range)	10.00 (18)	8.00 (11)	0.00 (3)	
Range (min-max)	20 (0-20)	15 (5-20)	4 (0-4)	
Future (25)				
Median (Interquartile range)	17.50 (21)	17.00 (12)	8.00 (9)	
Range (min-max)	23 (2-25)	18 (6-24)	11 (0-11)	
Self Blame (25)				
Median (Interquartile range)	23.00 (6)	14.00 (12)	0.00 (7)	
Range (min-max)	12 (13-25)	23 (0-23)	14 (0-14)	
Others (15)				
Median (Interquartile range)	11.00 (7)	7.00 (5)	5.00 (6)	
Range (min-max)	9 (6-15)	14 (1-15)	10 (1-11)	
Appropriateness of Grief (20)				
Median (Interquartile range)	14.00 (9)	9.00 (7)	1.00 (4)	
Range (min-max)	17 (0-17)	14 (6-20)	6 (0-6)	
Cherished Grief (15)				
Median (Interquartile range)	8.00 (13)	6.00 (5)	5.00 (6)	
Range (min-max)	14 (1-15)	11 (1-12)	7 (0-7)	
<b>Threatened Interpretation (20)</b>				
Median (Interquartile range)	14.00 (9)	14.00 (8)	1.00 (4)	
Range (min-max)	15 (5-20)	14 (6-20)	4 (0-4)	

 Table 5: Descriptive statistics from the GCQ

# Are there differences in birthparents experiences of grief compared to bereaved individuals? Do birthparents have more difficulty with blame, self, and a perceived lack of support from others?

Descriptive statistics and the small effect size indicating that birthparents have more negative grief cognitions confirmed the rationale for exploring further the differences between the birthparent and bereaved groups. Further analysis was conducted between the groups for three subtests of the GCQ; self, self-blame, and others (see table 5 for descriptive statistics). These subtests were selected as they were hypothesised from the qualitative research to be areas particularly challenging for birthparents. Non-parametric testing was chosen to explore further the difference between the groups, as the data does not consistently meet parametric assumptions. Field (2005) suggests use of the more conservative Kolmogorov-Smirnov Z test for sample sizes under 25. However, the Mann Whitney U was selected as it is a more robust test, and this project is a pilot study with a small sample size and taking an exploratory approach to statistical analysis.

A Mann-Whitney U test revealed a statistically significant difference in self-blame cognitions, with birthparents (median=23.00) reporting more self-blame cognitions than bereaved participants with a large effect size (median=14.00; U=15.50, z=-2.885, p=0.002, r=-0.60; see Figure 2). A Mann-Whitney U test revealed that birthparents (median=23.00) scored slightly higher in negative grief cognitions about self than the bereaved participants (median=16.00) with a medium effect size (U=40.50, z=-1.262, p=0.213, r=-0.26). A Mann-Whitney U test also revealed that birthparents (median=11.00) scored slightly higher in negative grief cognitions about others than the bereaved participants (median=7.00) with a medium effect size (U=32.00, z=-1.818, p=0.076, r=-0.38). Therefore, the analysis suggests that birthparents have more difficulty with negative grief cognitions of self-blame, self and others compared to the bereaved group with medium to large effect sizes. The self-blame finding is most robust with a significant effect and large effect size.

Figure 2: Boxplot of birthparent and bereaved groups on the self-blame subtest of the



# Are there similarities in birthparents' experience of grief compared to that of bereaved individuals?

The intention was to be able to explore if birthparents are grieving by testing for similarities in experience with bereaved individuals. Testing for equivalence has become increasingly recognised in psychology as a method of statistically testing for similarities (Lakens, 2017). Equivalence testing involves selecting an upper and lower limit as an equivalence margin, and testing whether the difference and confidence intervals fall within the margin (Walker & Nowacki, 2011). The researcher concluded that it is not appropriate to conduct equivalence testing on this data. A small sample size directly increases the confidence intervals, which results in no statistical power because the confidence intervals become larger than the equivalence margin (Lakens, 2017; Walker & Nowacki, 2011). Also, the data does not meet parametric assumptions and the most reported methods of equivalence testing identified by the researcher involved the use of means (Lakens, 2017).

#### Summary of results

There was a significant difference between the three groups in the total GCQ score, with exploration of post-hoc tasting indicating that the birthparents and bereavement groups were both experiencing significant more negative grief cognitions compared to the control group with a large effect size. Birthparents had slightly more difficulty with negative grief cognitions than the bereaved group with a small effect size. Further exploration of this difference at a subtest level indicated that birthparents likely have greater difficulty than

the bereaved individuals with negative grief cognitions regarding self-blame, self and others with medium to large effect sizes. The most robust result was for self-blame, with a small probability level and large effect size.

## DISCUSSION

# Do birthparents that have had a child removed from their care and bereaved individuals within addictions services experience grief compared to a general addictions population?

This study found that the birthparents and bereaved individuals reported significantly more grief cognitions compared to the control group, indicating that both groups have difficulty with grief cognitions as measured by the GCQ. The questionnaire was developed to measures negative grief cognitions associated with problematic grief (Boelen, van den Bout & van den Hout, 2003). Thus the birthparents and the bereaved individuals' higher total scores indicate that their grief cognitions are likely impacting on their ability to process their grief. The original GCQ studies related the grief cognitions to significantly greater difficulty with anxiety and depression as measured by a mental health questionnaire (Boelen & Lensvelt-Mulders, 2005; Boelen, van den Bout & van den Hout, 2003). The presence of anxiety and depression was also evident in our sample, with average scores over the clinical cut-offs on the measure of mental health (HADS). Comparison to normative data from a grieving general population (Boelen & Lensvelt-Mulders, 2005) showed that the addictions birthparents and bereaved individuals score much higher on negative grief cognitions indicating greater difficulties with grief. This highlights the level of complexity of processing grief and the likelihood of co-morbid mental health problems in the addictions population. This finding is consistent with current prevalence statistics identifying that 53% of individuals presenting for drug assessment in Scotland reported a co-occurring mental health problem (Information Services Division, 2017). However, the comparison with the normative data provided for the GCQ is limited by the high level of dispersion of scores and lack of clarity regarding a baseline score and level of severity on the measure.

#### Birthparents experiences of grief compared to bereaved individuals

This study found that the effect size for the difference in the grief cognitions for birthparents versus bereaved individuals was small. Further exploration at subtest level found that compared to the bereaved group, birthparents reported more negative grief cognitions in the self-blame, self and others subtests with medium to large effect sizes. This suggests that birthparents that have had a child removed from their care by social work have a grieving profile that is different from bereaved individuals who have experienced the death of someone close to them. The others subtest does suggest that birthparents have difficulty with negative cognitions about others support for them alluding to difficulty with social recognition regarding the loss of their child from their care. However, disenfranchised grief is about a loss not being recognised by others thus further research is need to explore societies perceptions of birthparents who have had children removed to explore fully this phenomenon.

The most robust effect in the analysis was for self-blame cognitions with a small probability value and large effect size. The self-blame subtest of the GCQ involves questions about responsibility for the loss and having not cared enough for the person. This subtest seems accurate in detecting birthparents' feelings of responsibility and blame as identified for mothers in previous qualitative studies (Schofield, et al., 2011; Hardesty & Black, 1999). De Simone's (1996) research with birthmothers who relinquished their child for adoption identified a significant association between feelings of shame and guilt and unresolved grief. Thus self-blame for birthparents that have had a child removed is likely to be a challenge to processing their loss.

#### Acceptability of grief questionnaire

This study also considered the feasibility of using the GCQ with a substance misuse population, thus completion rates and acceptability of the questionnaire were considered. All participants completed the GCQ, with no dropouts, suggesting the measure was acceptable to the population. The research team observed literacy issues during the study. Some potential participants were unable to take part as they were could not read. Some birthparents reported finding the adapted GCQ language of mourning challenging in relation to their child who was still alive (see appendix 3.6). However, this was not reflected in internal consistency testing as it was good (0.89) on the cherish grief subtest for birthparents where all three questions include the word mourn.

#### Feasibility of recruitment

This study also aimed to explore the feasibility of recruiting for this project and recruitment methods. Recruitment was a challenge for this study. The recruitment plan was 12-15 participants per month over 5-6 months. The recruitment strategy for the clinics involved attending the same clinic for two consecutive weeks, as the majority of patients attend fortnightly. Recruitment was resource intensive with the researcher recruiting 14 participants, from 30 half-day clinics, across the 3½month period, with nobody recruited at

20 of the clinics. Recruitment from the Clinical Psychologists was predominately from the field supervisor's caseload. Recruitment stopped in mid-June as planned. The majority of the clinics had been attended and the frequency of recruitment meant further time spent at clinics could achieve no further participants. Also recruitment from the field supervisor's caseload was complete.

There were several reasons the recruitment plan was not achieved. Firstly, the timeframe was reduced due to delays gaining in approval and was restricted due to the researchers training. Future studies could ensure that there is flexibility in the timescale to allow for on-going recruitment. Secondly, clinicians' engagement with the protocol and their approach to their patients was variable. Further training for staff could be beneficial in increasing engagement with the protocol. Thirdly, the question of whether the method of recruitment was most efficient for this population. Recruiting through clinics targeted a predominately drug misuse and poly-substance misuse population due to this group attending clinics to access a replacement regime script. They are a stigmatised, hard to reach population, who require flexibility in approach to engage in research. One study identified the benefits of employing workers with lived experience of substance misuse to engage the targeted population in research (Stewart, et al., 2012). A study exploring the motivations of injecting drug-users for engaging in research, identified that that economic gain was important but they were also motivated by benefits for themselves and others (Fry & Dwyer, 2001).

#### Suitability of design

A three-group, cross-sectional design was piloted. The study identified that within parents experiences of having children removed there is likely varying types of loss experiences. This was evident in the birthparents group as one participant was excluded due to their experience on the measure being different due to their partner preventing access. Future studies should have clearer defined inclusion criteria regarding social work removal specifying children in foster care or adopted would likely improve the birthparent sample for future studies.

A control group provided a baseline measure on the GCQ in substance misuse population whilst accounting for level and complexity of grief. However, the control group were small and variable in their experiences. An assumption was made that all participants would have experienced a death of someone close to them at some point in their lives. It is a limitation that participants' age was not collected, as this would have been beneficial in considering how representative the control group is of the substance misuse population as a whole. Although it is sound research design to include a control group, in clinical practice this group rarely exist. Quantitative research identified the high prevalence of loss in the substance misuse population at all stages of addiction and recovery (Furr, Johnson & Goodall, 2015). They also noted the possible challenges in engaging with grief work for this population as it requires engaging with intense emotions and shame related to loss caused by their substance use (Furr, Johnson & Goodall, 2015). Thus the pilot suggests that a three-group design is likely to be challenging.

#### CONCLUSIONS

This pilot study has indicated the benefits of using the GCQ with an addictions population and birthparents. Nonparametric testing indicates birthparents and the bereaved individuals experience greater difficulty with negative grief cognitions than an addictions control group, with birthparents having greater difficulty with self-blame, self and others cognitions. Further research to increase the sample size and power of the statistics would be beneficial in strengthening these findings. This study can make a number of useful recommendations for future research regarding feasibility and design. Further service user input regarding the wording of the adapted GCQ with birthparents would be beneficial to ensure it is fully accessible to this population. A two-group design should be considered, due to the challenges recruiting a control group, and the sample size calculated to allow for equivalence testing. This would allow for exploration of whether birthparents experience grief following removal of their child by statistically analysing for similarities with grieving bereaved individuals. The recruitment strategy could also be improved through use of experts by experience and service user involvement to ensure benefits of research to participants and others is highlighted.

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## Appendix 1.1 – Journal Convention Guidance Notes

#### **Requirements for Submitted Articles for Addictions Journal**

(Guidance from their website accessed 14<sup>th</sup> June 2017 http://www.addictionjournal.org/pages/authors#generalinformation)

Authors should pay special attention to the guidance on the website relating to the specific type of article being submitted. The manuscript should comprise a single Word file unless it is essential to put figures in other files. All pages should be numbered.

**Figures and tables:** All tables and figures should be cited in the text. Do not insert tables and figures into the main body of the text; instead, indicate where they should appear in the text and place them at the end of the document. Legends should include keys to any symbols. In the full-text online edition of the journal, figure legends may become truncated in abbreviated links to the full-screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

**Front sheet(s):** Front sheet(s) should always include title, list of authors, author affiliations and addresses, running head, word count (excluding abstract, references, tables, and figures), declarations of competing interest, and clinical trial registration details (if applicable).

#### Abstracts:

• Abstracts for research reports use the following headings: Aims (or Background and Aims, if appropriate), Design, Setting, Participants/Cases, Intervention(s) (and comparator(s)) (if appropriate), Measurements, Findings, Conclusions. Where it seems more appropriate, abstracts for research reports can be structured under the following headings: Aims (or Background and Aims, if appropriate), Methods, Results, Conclusions.

• Abstracts for review articles use the following headings: Aims (or Background and Aims, if appropriate), Methods, Results, Conclusions. Abstracts for case reports and case series use the following headings: Aims (or Background and Aims), Case Description(s), Conclusions.

• Abstracts for trial protocols use the following headings: Aims (or Background and Aims, if appropriate), Design, Setting, Participants, Measurements, Comments. Abstracts should generally be no more than **300 words**. Any numbers provided in the abstract must match exactly those given in the main body of the text or tables. With quantitative studies involving statistical tests, abstracts must provide p values or effect sizes with confidence intervals for key findings. The conclusion must provide the main generalisable statement resulting from the study; i.e. the sentence(s) that someone citing the study could use to describe the findings without modification. Do not use abbreviations in the abstract conclusion. Six to 10 key words should be provided.

**Null findings:** Authors should only report 'no difference' between conditions or lack of associations if they can demonstrate this by calculating Bayes Factors. A Bayes Factor of less than 0.3 would normally be required to be confident that there really is no difference or association. Otherwise null findings should be framed as 'the findings were inconclusive as to whether or not a difference/association was present' or some similar wording.

**P-values and confidence intervals:** Authors should cite exact p-values for primary statistical tests. Addiction adopts the conventional 5% value for statistical significance and does not accept terms such as 'trend' for cases where p<0.10. In general estimated values should include 95% confidence intervals or Bayesian credibility intervals.

**References:** References should follow the basic numbered Vancouver style. Provide up to the first six authors and then follow by et al, then the last author if this person is the senior author for the paper. Issue/part numbers are not required. Do not include citations to conference abstracts or unpublished work to support substantive claims but do use them if needed to give credit where appropriate. Please ensure that the introduction and discussion sections of your article cite the most recent relevant literature and not just literature from your own research group, region or country. Papers may include systematic reviews and one or two of the pivotal studies that a review has summarised.

Archiving of source material: Authors are invited to archive any web references before citing them, using WebCite ® technology. This service ensures that cited web material will remain available to readers in the future.

**Defamatory statements:** Authors should refrain from making defamatory statements about specific individuals or organisations, whether or not they believe these are justified.

We will continue to raise issues and make comments about the behaviour of sectors such as the alcohol industry, and we will analyse and critique research and claims made by vested interests.

**Hypothesis tests:** Addiction expects that authors claiming to test hypotheses will have preregistered these and the proposed analysis plan, with a date stamp, to provide evidence that the hypothesis was generated prior to viewing the results. A simple way to do this is through the Open Science Framework (<u>https://osf.io</u>). Hypotheses that have been preregistered can be given the label 'pre-registered hypothesis' with a link to the OSF reference.

**Permission to reprint source material:** If a paper uses all or parts of previously published material, the author must obtain permission from the copyright holder concerned. It is the author's responsibility to obtain these permissions in writing and provide copies to *Addiction*.

**Histograms:** Do not include histograms with three-dimensional blocks or shading as this can make interpretation difficult.

**Colour illustrations:** Authors are expected to pay the full cost for reproducing colour artwork. Therefore, please note that if there is colour artwork in your manuscript when it is accepted for publication, Wiley-Blackwell require you to complete and return a colour work agreement form before your paper can be published. Please note we can only accepted original copies of the form. Faxed or scanned forms are not acceptable.

**Preparation of electronic figures for publication:** Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (lineart) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible). For scanned images, the scanning resolution (at final image size) should be as follows to ensure good reproduction: lineart: >600 dpi; half-tones (including gel photographs): >300 dpi; figures containing both halftone and line images: >600 dpi. Further information can be obtained at Wiley-Blackwell 's Electronic Artwork Guidelines.

**Supporting information:** Additional material such as video clips and lengthy appendices (e.g. extensive reference lists or mathematical formulae/calculations), that are relevant to a particular article but not suitable or essential for the print edition of the journal, may also be considered for publication. Please refer to all supporting information in the manuscript using Table S1, Figure S1, etc., and supply such information as separate files (i.e. not embedded within the main manuscript). Further information on suitable file formats etc. may be found at Author Services.

**English-language editing:** If English is not the first language of authors, they are advised to have their manuscript edited by a native English speaker before submission. However, we will do our best to accommodate papers from authors in countries where the resources do not exist for this.

# Appendix 2.1 – Full database search strategy

- ("mother\*" or "wom?n" or "parenting" or "pregna\*" or "birth" or "child\*" or "son" or "daughter")
- ("alcohol\*" or (("drug\*/substance\*/addict\*" AND ("cocaine" or "heroin" or "metha\*" or "illicit" or "illegal" or "misuse" or "abuse")) or "rehabilitation" or "recovery")
- 3. ("perception\* N4/adj4 parent\*" or "perception\* N4/adj4 mother\* or "experience\* N4/adj4 mother\*" or "mothering N4/adj4 practic\*" or parenting N4/adj4 practic\*" or "parenting N4/adj4 skills" or "mothering N4/adj4 skills" "parent\* N4/adj4 behaviour\*" or "mother\* N4/adj4 behaviour\*" or (("mother AND (good or bad or unfit))")
- 4. ("qualitative" or "phenomenological" or "thematic analysis" or "grounded theory" or "narrative" or "discourse analysis" or "interview\*" or "focus group\*)

The themes were searched using the Boolean term AND as follows:

	(a) 1 AND 2	(b) a AND 3	(c) b AND 4
--	-------------	-------------	-------------

Search & Limits	Results	Interface	Date
Search strategy as described	475	EBSCOhost	9 <sup>th</sup> April
plus suitable EBSCOhost			2017
heading searches.			
Limits: Peer reviewed, English			
Search strategy as for	283	EBSCOhost	9 <sup>th</sup> April
PsychInfo with adjustments for			2017
American spelling (e.g.			
behaviour to behavior).			
Limits: Peer reviewed, English			
Search strategy as for	396	EBSCOhost	9 <sup>th</sup> April
PsychInfo.			2017
Limits: Academic Journals,			
English			
Search strategy as for	123	EBSCOhost	9 <sup>th</sup> April
PsychInfo.			2017
Limits: Peer reviewed.			
Search strategy as described	760	Ovid	13 <sup>th</sup>
plus suitable Ovid search			April
headings.			2017
Limits: English			
Search strategy as described	303	ProQuest	16 <sup>th</sup>
above.			April
			2017
Limits: Peer reviewed, English			
	Search & LimitsSearch strategy as describedplus suitable EBSCOhostheading searches.Limits: Peer reviewed, EnglishSearch strategy as forPsychInfo with adjustments forAmerican spelling (e.g.behaviour to behavior).Limits: Peer reviewed, EnglishSearch strategy as forPsychInfo.Limits: Academic Journals,EnglishSearch strategy as forPsychInfo.Limits: Peer reviewed.Search strategy as forPsychInfo.Limits: Peer reviewed.Search strategy as describedplus suitable Ovid searchheadings.Limits: EnglishSearch strategy as describedabove.Limits: Peer reviewed, English	Search & LimitsResultsSearch strategy as described plus suitable EBSCOhost heading searches.475Limits: Peer reviewed, English283Search strategy as for PsychInfo with adjustments for American spelling (e.g. behaviour to behavior).283Limits: Peer reviewed, English475Search strategy as for PsychInfo.396Search strategy as for PsychInfo.396Search strategy as for PsychInfo.123Limits: Academic Journals, English123Search strategy as for PsychInfo.123Search strategy as described plus suitable Ovid search headings.760Limits: English303Search strategy as described plus suitable Ovid search headings.303Limits: English303Search strategy as described plus suitable Ovid search headings.303Limits: English303Search strategy as described plus suitable Ovid search headings.303Limits: English303	Search & LimitsResultsInterfaceSearch strategy as described plus suitable EBSCOhost heading searches.475EBSCOhost heading searches.Limits: Peer reviewed, English283EBSCOhostSearch strategy as for American spelling (e.g. behaviour to behavior).283EBSCOhostLimits: Peer reviewed, English283EBSCOhostSearch strategy as for PsychInfo.396EBSCOhostSearch strategy as for PsychInfo.396EBSCOhostLimits: Academic Journals, English123EBSCOhostSearch strategy as for PsychInfo.123EBSCOhostSearch strategy as for PsychInfo.123EBSCOhostLimits: Peer reviewed.760OvidLimits: Peer reviewed.303ProQuestabove.303ProQuestabove.Limits: Peer reviewed, English303

# Appendix 2.2 – Electronic Search Strategy and Results

# Appendix 2.3 – Qualitative Appraisal Tool

Operationalised version of Table 4 – Summary criteria for appraising qualitative research studies (pg. 114)

Stages	<b>Essential Criteria</b>	Specific Prompts	Tick
Scope and	Clear statement of, and	Clarity of focus demonstrated	
purpose	rationale for, research	Explicit purpose given, such as	
	question/aims/ purpose	descriptive/explanatory intent, theory	
		building, hypothesis testing	
		Link between research and existing	
		knowledge demonstrated	
	Study thoroughly	Evidence of systematic approach to	
	contextualised by	literature review, location of literature	
	existing literature	to contextualise the findings, or both.	
Design	Methods/design	Rationale given for use of qualitative	
	apparent, and	design	
	consistent with	Discussion of	
	research intent	epistemological/ontological grounding	
		Rational explored for specific	
		qualitative method (e.g. ethnography,	
		grounded theory, phenomenology)	
		Discussion of why particular method	
		chosen is most	
		appropriate/sensitive/relevant for	
		research questions/aims	
		Setting appropriate	
	Data collection	Were data collection methods	
	strategy apparent and	appropriate for type of data required	
	appropriate	and for specific qualitative methods?	
		Were they likely to capture the	
		complexity/diversity of experience and	
		illuminate context in sufficient detail?	
		Was triangulation of data sources used	
		if appropriate?	
Sampling	Sample and sampling	Selection criteria detailed and	
Strategy	method appropriate	description of how sampling was	
		undertaken	
		Justification for sampling strategy	
		given	
		Thickness of description likely to be	
		achieved from sampling	
		Any disparity between planned and	
		actual sample explained.	

Stages (cont)	Essential Criteria	teria Specific Prompts '				
Analysis	Analytic approach	Approach made explicit (e.g. thematic				
	appropriate	distillation, constant comparative				
		method, grounded theory)				
		Was it appropriate for the qualitative				
		method chosen?				
		Was data managed by software				
		package or by hand and why?				
		Discussion of how coding				
		systems/conceptual frameworks				
		evolved				
		How was the context of data retained				
		during analysis?				
		Evidence that the subjective meanings				
		Exidence of more then one mesoarcher				
		involved in stages of appropriate				
		anistamological/theoretical stance				
		Did research participants have any				
		involvement in analysis (e.g. member				
		checking)				
		Evidence provided that data research				
		saturation or discussion/rationale if it				
		did not				
		Evidence that deviant data was sought,				
		or discussion/rationale if it was not				
Interpretation	Context described and	Description of social/physical and				
-	taken account of in	interpersonal contexts of data				
	interpretation	collection				
		Evidence that researcher spend time				
		'dwelling with the data', interrogating				
		it for competing/alternative				
		explanations of phenomena				
	Clear audit trail given	Sufficient discussion of research				
		processes such that others can follow				
	Determent to support	decision trail .				
	Data used to support	Extensive use of field notes				
	interpretation	discussion of findings				
		Clear exposition of how interpretation				
		lead to conclusions				
Reflexivity	Research reflexivity	Discussion of relationship between				
Reflexivity	demonstrated	research and participants during				
		fieldwork				
		Demonstration of researcher's				
		influence on stages of research process				
		Evidence of self-awareness/insight				
		Documentation of effects of the				
		research on researcher				
		Evidence of how				
		problems/complications met were				
		dealt with				

Stages (cont)	Essential Criteria	Specific Prompts	Tick
Ethical	Demonstration of	Ethical committee approval granted	
Dimensions	sensitivity to ethical	Clear commitment to integrity,	
	concerns	honesty, transparency, equality and	
		mutual respect in relationships with	
		participants	
		Evidence of fair dealing with all	
		research participants	
		Recording of dilemmas met and how	
		resolved in relation to ethical issues	
		Documentation of how autonomy,	
		consent, confidentiality, anonymity	
		were managed.	
<b>Relevance and</b>	Relevance and	Sufficient evidence for typicality	
transferability	transferability evident	specificity to be assessed	
		Analysis interwoven with existing	
		theories and other relevant explanatory	
		literature drawn from similar settings	
		and studies	
		Discussion of how explanatory	
		propositions/emergent theory may fit	
		other contexts	
		Limitations/weakness of study clearly	
		outlined	
		Clearly resonates with other	
		knowledge and experience	
		Results/conclusions obviously	
		supported by evidence	
		Interpretations plausible and 'make	
		sense'	
		Provides insights and increases	
		understanding	
		Significance for current policy and	
		practice outlined	
		Assessment of value/empowerment for	
		participants	
		Outline further directions for	
		investigation	4
		Comment on whether aims/purpose of	
		research were achieved	

	Unplanned pregnancy anxiety	Child as motivation	Ambivalence between hope for parenting and guilt for consequences	Minimal parenting	Separation	Intervening Factors	Redefining maternal identity
Silva, et al., (2012)	Circumstances for substance abuse during pregnancy - unexpected - feel unprepared	Motherhood as motivation/ salvation. Pregnancy as a time of change	Ambivalence between addiction and pregnancy/ parenting - hope for motherhood versus guilt and despair for harm caused - normalise drug use to cope with guilt	Functional (minimal) parenting - meeting basic needs - minimum doses to facilitate parenting - lack availability	Family member carrying out mothering role – challenging, family arguments	Intervening factors: family support to parental role - grandparent involvement, excessive control - role of partners, helpful if abstain, separation if not - helpful healthcare professionals	X
Haritavorn (2016)	Anxiety about pregnancy and childbirth - feels incompatible with drugs - unplanned	Wanting to be a good 'maae' (mother) - turning point - dream of being a good mother	Coping with baby suffering withdrawal – blame themselves	X	Withdrawing: letting them go - relinquish care to relatives - fear stigma of others - fear impact of environment of drug use	Seeking help: the importance of family - sibling or parental supports - family exerting influence	X
Secco, et al., (2014)	X	Choice for mothering - give up drugs for children - desire to be more present	X	Subtheme: diminished performed mothering - negative mothering, focus on drugs - physical care only	Subtheme: Interrupted mothering - physical separation or inability to provide care - criminal activity - distressing	Subtheme: role of own mother and/or social services - encouraging recovery by highlighting risk of removal	Redefined maternal identity - reversal of diminished mothering - lost preoccupation with drugs, focus on child - continued diminished identity when child doesn't accept recovery

# Appendix 2.4 – Results of reciprocal translation synthesis

Table continued.	Unplanned pregnancy anxiety	Child as motivation	Ambivalence between hope for parenting and guilt for consequences	Minimal parenting	Separation	Intervening Factors	Redefining maternal identity
Cleveland, Bonugli & McGlothen (2016)	Facing the realities of pregnancy complicated by substance use, trauma and loss - unplanned - previous pregnancy/birth traumas	Finding a higher meaning - pregnancy powerful motivator - change for sake of unborn child	<b>Dealing with</b> <b>consequences</b> - guilt/shame in observing baby in withdrawal - active involvement in caring for infant whilst withdrawing helps	X	Looking towards a future with my child - constant fear of separation, desire to keep their children	Managing the details of daily life - Child Protective Service experienced with embarrassment - strategies for preventing relapse: physical distance from past drug use or relapse-prevention strategies.	Х
Sorbo, Beveridge & Drapeau (2009)	X	Children as ultimate motivators - reason for recovery	<b>Obligation and</b> <b>responsibility</b> - sense of obligation to be abstinent in pregnancy - desire for a healthy baby	X	Experience of having children removed – in total denial, questioning why removed.	<b>Recovery</b> – importance of external supports	Interrupted identity & 'who I am, what I am becoming?' - addiction a blip in identity development - dependable, reliable and strength important for recovery
Hardesty & Black (1999)	X	Centrality of motherhood and mother work - despite substance misuse desire to mother - child more important than self	X	Doing it all - drug work versus mother work - claim meeting all child's needs - drug use facilitates parenting	Falling through or failing as mothers - mothering no longer good enough - drug work takes over - lost balance - voluntary care more protective of identity than removed by services	X	Recovering the mother identity - mother work becomes hope - reliance on acceptance of recovery by children - children don't always accept recovery or high mother expectations can risk relapse

\* Bold is a theme in the paper

X is not covered in the paper

# **Appendix 3.1 – Approval Letters**

NHS REC agreed favourable opinion on 13<sup>th</sup> December 2016. This was following a provisional approval decision on 14<sup>th</sup> October 2016 requesting further rationale for recruitment from waiting rooms. Further evidence was provided that this was the safest option due to the lack of consistently available private rooms at clinics. Both REC and R&D approved a non-substantial amendment submitted due to the main research site moving office on the 16<sup>th</sup> January 2017 requiring amendments to telephone numbers on the patient information sheet (version 4) and support services information sheet (version 2). Head of department agreement regarding the practicalities of implementing the protocol was required to maintain good relationships with the team and was agreed in February 2017.



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#### West of Scotland REC 4

West Ambulatory Care Hospital Dalnair Street Yorkhill Glasgow www.nhsggc.org.uk

Date13 December 2016Direct line0141-232-1806e-mailWosrec4@ggc.scot.nhs.uk

Version 2 – Two versions of the protocol were listed in "Approved Documents" this has been amended to include only the most recent version

Dear Ms Anderson

Study title:	Identifying and exploring grief in parents who have had children removed from their care within Addictions Services: A pilot study
	Services. A prior study.
REC reference:	16/WS/0195
Protocol number:	L160602_EXT (NHSL R&D)
RAS project ID:	206476

Thank you for your submission of 02 December 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Sophie Bagnall, <u>wosrec4@ggc.scot.nhs.uk</u>.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, <u>www.hra.nhs.uk</u> or at <u>http://www.rdforum.nhs.uk</u>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (<u>catherineblewett@nhs.net</u>), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Project Advertising Grief in Addictions - Tracked Changes]		04 November 2016
Copies of advertisement materials for research participants [Project Advertising Grief in Addictions - Clean]		04 November 2016
Covering letter on headed paper [Cover letter in response to provisional decision]		11 November 2016
Letter from funder [University of Glasgow Proceed to Ethics Support Letter]		19 May 2016
Letter from sponsor [Sponsorship Confirmation Letter]		29 August 2016
Non-validated questionnaire [Quantity Frequency Questionnaire for Grief in Addictions Service Project]		16 September 2016
Non-validated questionnaire [Demographic Information Questionnaire for Grief in Addictions Service Research Project]		16 September 2016
Other [Support Service Sheet for Grief in Addictions Service Project]		16 September 2016
Other [Letter of Support from Head of Service]		11 November 2016
Participant consent form [Consent Form for Project on Grief in Addictions Service - Tracked Changes]		04 November 2016
Participant consent form [Consent Form for Project Grief in Addictions Service - Clean ]		04 November 2016
Participant information sheet (PIS) [Patient Informations Sheet for Grief in Additions Project - Tracked changes]		02 December 2016
Participant information sheet (PIS) [Patient Information Sheet for Grief in Addictions Project - clean version]		02 December 2016
REC Application Form [REC_Form_16092016]		16 September 2016
Research protocol or project proposal [Protocol for Grief in Addictions Project]		29 October 2016
Summary CV for Chief Investigator (CI) [Ruth Anderson CV 2016]		
Summary CV for supervisor (student research) [AJackson short CV]		
Validated questionnaire [Grief Cognition Questionnaire Adapted for Parents]		16 September 2016
Validated questionnaire [Greif Cognitions Questionnaire for Bereavement]		16 September 2016
Validated questionnaire [HADS]		

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

#### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <u>http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/</u>

#### **HRA** Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

#### 16/WS/0195

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

#### On Behalf of Dr Ken James Chair

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to:

Mr Raymond Hamill Ms Elaine O'Neill, NHS Greater Glasgow and Clyde

# NHS Greater Glasgow & Clyde Research and Development Approval Letter (host

site):



R&D Management Office West Glasgow ACH

**Dalnair Street** 

Glasgow G3 8SW

Administrator: Mrs Elaine O'Neill Telephone Number: 0141 232 1815 E-Mail: elaine.o'neill2@ggc.scot.nhs.uk Website: www.nhsggc.org.uk/r&d

15 December 2016

Dr Lynda Russell Clinical Psychologist North West Community Addictions Team Possilpark Health and Care Centre Glasgow G22 5AP

#### NHS GG&C Board Approval

Dear Dr L Russell,

Study Title:	Identifying and exploring grief in parents who have had children removed from their care within Addictions Services: A pilot study.
Principal Investigator:	Dr Lynda Russell
GG&C HB site	Community Addictions Teams
Sponsor	NHS Lanarkshire
R&D reference:	GN16MH564
REC reference:	16/WS/0195
Protocol no:	V8; 29/10/16

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### **Conditions of Approval**

- 1. For Clinical Trials as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (<u>www.nhsggc.org.uk/content/default.asp?page=s1411</u>), evidence of such training to be filed in the site file.
- 2. For all studies the following information is required during their lifespan.
  - a. Recruitment Numbers on a monthly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

#### Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Mrs Elaine O'Neill Senior Research Administrator

Cc: Ms Ruth Anderson (student/Cl) Mr Raymond Hamill (Sponsor)

## NHS Lanarkshire Research & Development Letter (Sponsor):

NHS Lanarkshire Research & Development: Management Approval Letter

Project I.D. Number L16062\_EXT



Ms Ruth M Anderson Trainee Clinical Psychologist NHS Lanarkshire CAMHS Service 49 Airbles Road MOTHERWELL ML1 2TJ R&D Department Corporate Services Building Monklands Hospital Monkscourt Avenue AIRDRIE ML6 0JS

Date	21.12.16
Enquiries to	Elizabeth McGonigal,
	R&D Facilitator
Direct Line	01236 712459
Email	Elizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Ruth,

Project title: Identifying and exploring grief in parents who have had children removed from their care within Addictions Services: A pilot study

#### R&D ID: L16062\_EXT

I am writing to you as Chief Investigator of the above study, which received a favourable ethical opinion on 13 December 2016.

As you are aware, NHS Lanarkshire has agreed to be the Sponsor for your study. On its behalf, the R&D Department has a number of responsibilities; these include ensuring that you understand your own role as Chief Investigator of this study. To help with this we have outlined the responsibilities of the Chief Investigator in the attached document for you information.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

# Appendix 3.2 – Project Protocol – Major Research Project Proposal (Version 8, 29/10/16)

<u>**Title:**</u> Identifying and exploring grief in parents who have had children removed from their care within Addictions Services: A pilot study.

### **Abstract**

*Background* Grief is a reaction to a loss that involves a number of feelings and symptoms. Many individuals recover from grief without formal supports; however, others have ongoing difficulties with grief termed complicated grief. It has been identified that negative grief cognitions may play a role in grief being more complicated to process. Many factors highlighted by qualitative research may make grief more complicated for parents who have had a child removed from their care including; self-blame, guilt, challenges to identity and others perception of the removal.

*Aims* This project aims to identify if the removal of a child from parents within Addictions Services results in a grief reaction and explore the negative grief cognitions that may influence coping following the loss.

*Methods* A negative grief cognitions measure will be completed with three groups of participants within the addictions population; (1) parents who have had a child removed from their care, (2) a bereavement group with complicated grief and on-going distress and (3) a control group who have had a bereavement and are no longer distressed. Demographic information will be gathered along with a mood measure of depression and anxiety and measures of substance use.

*Applications* Understanding parent's negative grief cognitions in response to having their child removed will inform the development of interventions.

## Word Count - 215

#### **Introduction**

In Scotland around 150,000 children are affected by parental substance misuse; however, this is thought to be an underestimate due to a lack of good quality evidence (Looking Beyond Risk, 2006). Looking Beyond Risk (2006) identified from the literature that substance misuse has a negative impact on parenting ability and increases the risk of all types of abuse, particularly when present with other environmental factors such as social isolation. This is reflected in the legislation as the Adoption and Children (Scotland) Act (2007) highlights the need for supports for birth parents at all stages of the adoption process. However, Memarnia and colleagues (2015) identified that despite noting the need for supports, this was not as evident in research and practice.

Schofield and colleagues (2011) qualitative study identified most parents who had a child removed to foster care described experiences of grief. Grief is a loss that results in a range of emotions and symptoms (Corr, 2002). Shear, Simon and Wall and colleagues (2011) literature review identified five studies that indicate many people respond to a death with an acute grief response that reduces over time as the death is made sense of. They identify a further five studies that indicate that some individuals develop complicated grief, that is ongoing distress related to a death, noting evidence for complicated grief impacting negatively on social functioning, sleep and activity levels, increased smoking, use of alcohol and suicidal ideation. Grief research is developing to consider the impact of other losses. Neil (2013) identified 67% of mothers and 56% of fathers who had a child removed from their care had overall scores on a self-report measure of mental health symptoms in the clinical range. This indicates a significant impact on mental health and suggests the presence of grief, which requires further exploration to improve outcomes for parents.

Studies have begun to identify factors that may influence grief following the removal of a child. One factor is the emotions that parents experience. De Simone (1996) found a significant positive correlation between grief problems on a grief inventory and the emotions of shame and guilt in birthmothers. Schofield and colleagues (2011) noted similar emotions from interviewing birthmothers who described feelings of blame and responsibility about their child being in the care system. However, Schofield and colleagues (2011) found that some mothers described externalising their blame with feelings of anger towards services or a partner. Memarnia and colleagues (2015) also identified anger from parents towards services in their theme of parents feeling unsupported to improve their circumstances. Neil (2013) found elevated scores in the paranoid thoughts subtest, such as blaming others. Neil drew on Schofield's conclusions suggesting that this was due to parent's attempts to place blame on others. Further research is needed to explore the role of blame as the findings are mixed currently.

Another factor is how others respond to the loss. Doka (1989) developed the term disenfranchised grief that is a loss that is not socially validated, acknowledged or

mourned publicly. Doka (2002) posits that when a loss is not recognised, it can result in less access to supports and increase the complexity of the emotional response. Removal of a child into care is likely to be experienced by the parent as a disenfranchised grief and has been highlighted theoretically in qualitative studies (Schofield et al, 2011; Memarnia et al 2015). Further quantitative research with both mothers and fathers is needed to explore how they feel others perceive their loss, as this will have implications on processing the loss.

A final factor is parent's identity. Qualitative studies have identified the significant impact that removal of a child has on parent's identity. Studies describe mothers feeling lost or different about their identity and questioning how others might perceive them (Memarnia et al, 2015; Schofield et al, 2011). Ongoing contact and the ambiguous nature of the loss of the child still being alive also makes managing identity and processing grief more challenging (Memarnia et al., 2015). However, quantitative research has not explored the impact that this challenge to identity has on the parent's beliefs, with some studies noting the role of negative global beliefs in problems processing grief (Boelen et al, 2003).

The current literature suggests that removal of a child is experienced by parents as grief, with a range of emotions of self-blame, anger and the challenge to identity and ambiguous nature of the loss and lack of support from others all appear to be important factors that may influence how well the grief is processed. However, these studies are predominately qualitative, rarely used formal measures, often did not include fathers and did not consider how the grief experienced by parents having a child removed compares with other losses. Quantitative research is needed to identify if this is grief and consider how it compares with other losses to inform understanding of this loss.

#### Aims and hypotheses

The project aims to explore the following questions:

- Do parents who have had a child removed from their care within Addictions Services experience a grief reaction?
- How does this grief reaction compare to the grief experienced by people having difficulty grieving the loss of a loved one?

The independent variable is loss, either of a child removed by services or death. This variable consists of three groups; (1) parent who had a child removed from their care

(2) bereavement due to death of a significant other that causes distress, and (3) control group with historical bereavement that has been processed. The dependent variable is grief. The hypothesis is that group (1) and (2) will experience higher levels of grief compared with (3) control group, identifying group (1) as experiencing a grief reaction.

### **Plan of Investigation**

#### **Participants**

Participants will be patients of the NHS Greater Glasgow and Clyde Addictions Service, North West Team, which includes three Community Addictions Teams (CATs), and patients of Clinical Psychologists within the wider Addictions Service. As patients of the service, participants will have clinically significant problems with substance misuse as defined by the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10; World Health Organisation, 2010). This is termed as dependence syndrome, which includes abstinent, replacement regimes (e.g. methadone) or blocking substances (e.g. disulfiram for alcohol), actively dependent, continuous or episodic use.

#### Inclusion and Exclusion Criteria

<u>Inclusion criteria</u> will be broad to include any parent who has had a child removed or a person who has experienced bereavement. The ongoing bereavement group will have clinically significant levels of distress, which will be self-diagnosed with support from a description on the demographic sheet. The control group will have self-diagnosed as no longer having distress regarding bereavement. All patients over 18 years old of both genders with adequate literacy skills will be included. All dependence diagnostic groups will be included; dependent, replacement regime or abstinent as the services includes all these groups.

Exclusion criteria: participants who are intoxicated to a degree that they are unable to provide informed consent or are highly distressed about their loss and young parents under 18 years old. Patients will be excluded if they have distress due to both removal of a child and bereavement.

#### **Recruitment Procedures**

The researcher will disseminate information and inclusion/exclusion criteria to the clinicians of the North West Addictions Team and Clinical Psychologists of the

Addictions Service. This aims to allow clinicians to independently identify any patients on their caseload who they can provide with information about the project. Posters will be placed in the waiting rooms where the researcher will be attending clinics advising participants to discuss the project with their worker and identifying when a researcher will be present at clinic. It is explicitly outlined on the poster that questionnaires will be completed in the waiting room and a private room can be arranged on request out with the clinic. A researcher will be present in the waiting room during clinics. They will be identified by a name badge and pointed out to all clients by administration/secretarial staff on their arrival to the clinic. Participants will be asked if they wish to take part now or if they wish to take more time to consider before completing informed consent. Participants will be recruited in this way from the waiting room by the researcher or field supervisor. There is the possibility that a private room could be available at one of the North West CAT clinics following the team moving office. If this is available it will be utilised by the research team and workers will direct clients who are interested in the project to the researcher. Clinical Psychologists will recruit from their caseloads in outpatient clinics.

#### Measures

<u>Demographic information</u> will be gathered to confirm group allocation. It will ask if participants have had any children removed, if so how many and if they are distressed. It will also ask if they have experienced bereavement, how long ago it was and if they are distressed. A definition of distress will be provided to support self-diagnosis of distress.

The Grief Cognitions Questionnaire (GCQ; Boelen et al, 2003) will be used to identify the presence of negative beliefs. Boelen and colleagues (2003) identified **four areas** of negative cognitions associated with poor emotional outcomes after a death and developed nine subtests to cover these; (1) **global beliefs** – self, world, life, future, (2) **self-blame**, (3) **others reaction**, (4) appropriateness, cherish grief and threatening **interpretation of grief** (see appendix 2). It is a self-report questionnaire made up of 38 questions that asks the rater to respond on a six-point scale (scored 0-5) with a higher score indicating greater grief problems. The questions can be personalised and the author has been contacted and permission given to reword this questionnaire for those who have had children removed e.g. "Since (insert name) is dead, I think I am worthless" to "Since my child was removed from my care, I think I am worthless".

questionnaire through online research recruiting bereaved individuals and found through factor analysis that the questions loaded onto the nine factors and there was adequate internal consistency.

<u>The Hospital Anxiety and Depression Scale</u> (HADS; Snaith & Zigmond, 1994) will be used. It consists of fourteen questions split into two subtests of anxiety and depression. A higher score indicates greater difficulties with each subtest totaling 21 with a score of 8 or more or each scale indicating clinical problems. McPherson and Martin (2011) reviewed the use of the HADS in an alcohol-dependent population concluding that it is likely to be appropriate for use, identifying some challenges with factor analysis but a good level of internal consistency.

<u>Information about substance use</u> will also be gathered; type of substance, frequency of use and quantity of use.

#### Design

A cross sectional study will be undertaken exploring grief cognitions between three groups who have experienced different types of loss in an addictions population.

#### **Research Procedures**

Participants who meet the inclusion criteria and can provide informed consent will be provided with a questionnaire pack including; the demographic question sheets, GCQ, HADS and quantity/frequency substance use measure to complete in the presence of the research team or their clinician. The questionnaire packs will look the same for both parents and the bereavement groups. The parent's pack with have the GCQ adapted for parents and the bereavement group will have the GCQ. The packs will be identified by having parent or bereavement written on the pack so participants can be shown the pack and choose the pack relating to them without having to verbalise which group they are in. This is thought to take around 30 minutes; however, the intention is to trial this with an addictions recovery group following ethical approval to ensure appropriateness of information sheets and questionnaires.

#### Data Analysis

From consultation with the Robertson Centre, the researcher is aware that adding a control group for this analysis is vital in being able to identify that what is being is distress due to grief and not related to addiction. Data analysis will look at differences

between the three groups using Analysis of Variance (ANOVA) or Kruskal Wallis depending on parametric assumptions. Group (1) and (2) will be compared looking for differences using t-tests or Mann-Whitney U. The Robertson Centre advised that looking at similarities between these groups is suitable using equivalence testing to identify if the grief reaction is similar. Demographic information, substance use and the HADS will be used to ensure the groups are similar and consider any other influencing factors.

## Justification of sample size

Consultation with the Robertson Centre confirmed that if there are no similar studies it is a pilot study and sample size calculations are tentative. Sim and Lewis (2012) suggest that a reasonable sample size for a pilot study is 50. This would suggest the rationale for a minimum of 25 participants per group (n=75). A case note audit of a sample of clinicians in the service is currently under way by the field supervisor. Personal communication with the field supervisor indicates early figures suggesting that for the North West Addictions team's active caseload of around 3000 patients, around 26% have bereavement issues and 19% have had a child removed. Personal communication with the field supervisor identified that the patients of North West Community Addiction Team (CAT) attend either the CAT clinics, a health centre or their own GP practice, with attendance rate of around 10 to 40 per clinic. Therefore recruitment appears feasible with a timescale of 5-6 months, which is 12-15 participants per month. The recruitment rate and which clinics to attend will be reviewed during data collection.

#### Settings and Equipment

The participants will be seen in the waiting room during clinics in the CAT team bases, satellite clinics or at GP practices by the researcher or field supervisor. The Clinical Psychologists will see participants in their outpatient clinics. The measures and costs of copying these have been calculated.

#### Health and Safety Issues (see appendix 1)

#### Researcher Safety Issues

The researcher will attend keyworkers clinics at the North West CAT team bases, satellite clinics and GP practices. The researcher will take time to familiarise themselves with the safety procedures for these environments.

### Participant Safety Issues

Completing the questionnaires could cause distress for the participants. Therefore, questionnaires will be completed in the presence of the researcher or clinician so participants can be reminded that they can stop at anytime, immediate support provided and further support sought from the addictions team in a private room. The participants will meet the researcher in the waiting room prior to their usual clinic appointment. The private room available if they do become distressed will be the room they are waiting to become available to see their worker in for their appointment. Following completion the researcher will enquire directly about their mood and provide written information about available supports. Any concerns regarding risk or clinical concerns (e.g. clinically significant HADS or GCQ scores) arising from the questionnaires will be shared with an appropriate member of the clinical team to inform effective clinical practice.

## **Ethical Issues**

The project has been submitted to NHS Lanarkshire Research and Development as the researchers employee for sponsorship. The project is also being submitted to NHS Greater Glasgow and Clyde Research and Development and NHS Research Ethics Committee for approval.

The project will aim to not include anyone who is highly intoxicated or experienced a recent loss and is highly distressed.

#### **Financial Issues**

Costs for the project are photocopying and stationary costs which are outlined in appendix 2.

## <u>Timetable</u>

	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
	15	15	16	16	16	16	16	16	16	16	16	16	16	16	17	17	17	17	17	17
Outline																				
Draft																				
Proposal																				
Proposal																				
Blind																				
Marking																				
Proposal																				
Corrections																				
Materials																				
development																				
Ethics &																				
R&D																				
Prep for data																				
collection																				
Staff																				
consultation																				
Recruitment																				
Data																				
collection &																				
scoring																				
Data analysis																				
Writing up																				
Final Report																				

## **Practical Applications**

This project aims to inform the field supervisors post-doctoral research, which aims to provide support for parents in the Addictions Service following the removal of their children by developing training for staff and a therapeutic group for parents. This project will support the development of the training and therapeutic group as it will hopefully describe the experience of grief that parents have which will be insightful for informing approaches and practice.

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## WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW DOCTORATE IN CLINICAL PSYCHOLOGY HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Identifying and exploring grief in parents who have had children removed from their care within Addictions Services
2. Trainee	Ruth Anderson
3. University Supervisor	Dr Alison Jackson
4. Other Supervisor(s)	Dr Lynda Russell
5. Local Lead Clinician	Dr Lynda Russell
6. Participants: (age, group or sub- group, pre- or post-treatment, etc)	Participants will be patients of NHS Greater Glasgow & Clyde Addictions Service, three groups: (1) parents who have had a child removed and (2) loss due to bereavement and on-going distress and (3) loss due to bereavement resolved grief. Participants will be 18 years and over, of both genders and have an addictions diagnosis (current use or abstinent).
7. Procedures to be applied (eg, questionnaire, interview, etc)	Clinicians in the team will be aware of the project and share information about the project verbally and in writing prior to participants attending a clinic when the researcher is present. The researcher or supervisor will seek informed consent following clarifying participants understand of the project. Information sheets will outline suitable participants e.g. what on- going distress is in relation to bereavement to help identify which group. Participants will complete a demographic form asking about details of the loss to confirm group identification. The Grief Cognitions Questionnaire, Hospital Anxiety and Depression Scale and frequency/quantity measure of substance use will also be administered.

<ul><li>8. Setting (where will procedures be carried out?)</li><li>i) Details of all settings</li></ul>	Participants will be met within NHS clinics, which are run at NHS sites, such as the North West Addictions team base, and GP practices.
ii) Are home visits involved	No

9. Potential Risk (for resear safety): i) ii) iii)	Factors Considered rcher and participant Participants Procedures Settings	<ul> <li>i) An addictions population is a high risk group as there is potential they may be intoxicated, they are more likely to have poor emotional regulation and coping strategies, high levels of comorbidity with mental health problems and forensic history.</li> <li>ii) The procedure may cause distress as questionnaires are regarding grief experiences, mood and demographic questionnaires ask for details regarding distressing situations (removal of child or death of loved one). However, these are similar areas that maybe raised in clinical practice.</li> <li>iii) Participants will be met at normal Addictions team clinics, either at in NHS clinical spaces or GP practices.</li> </ul>
10 10 minimise i) ii) iii)	. Actions to risk (refer to 9) Participants Procedures Settings	<ul> <li>i) Participants who are highly intoxicated or distressed, will be excluded from the study. These factors will be identified on discussing the information sheet and seeking informed consent. Participants are being met in clinic setting and will complete the measures in person, meaning the clinician will be working in close proximity to the team.</li> <li>ii) If participants are highly intoxicated or distressed on discussing the project, they will be excluded from the study and support sought from the team. The information sheet will advise participants of their right to withdraw at any time. The questionnaires will be completed in the presence of the research team so the researcher can support the participants. If a participant does become distressed (e.g. very tearful) the researcher will discontinue the procedure immediately and seek support from a suitable team member present at the clinic.</li> </ul>

The researcher will enquire into how
participants are feeling upon completing the
questionnaires and all participants will be
provided with a sheet of support
services/telephone numbers available to them if
they need support following leaving the clinic.
Any concerns identified regarding the
participant's mental health during scoring the
questionnaires will be shared directly with a
suitable team member e.g. clinically significant
HADS score, to ensure this need is being met
clinically.
-
iii) The researcher will adhere to the local
specific safety policies and ensure to explore
these prior to meeting with participants for
each premises, such as use and presence of
safety alarms.
-

Trainee signature:		Date:
University supervise	or signature:	Date:

## **RESEARCH EQUIPMENT, CONSUMABLES AND EXPENSES**

 Trainee ...Ruth Anderson.....

 Year of Course ...2<sup>nd</sup> Year.....

 Intake Year...2014......

Please refer to latest stationary costs list (available from student support team)

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	Paper (5 reams)	
	Coloured Paper (1 ream) Envelopes A4 (1 box of 250)	Subtotal: £22.47
Postage	N/A	Subtotal: £0
Photocopying and Laser Printing	Photocopying (2,200 sheets)	Subtotal: £110.00
Equipment and Software	Possibly use of laptop, as NHS Lanarkshire employee and NHS GGC project. May require IT support.	Subtotal: £0
Measures	Grief Cognition Questionnaire Health Anxiety & Depression Scale (HADS) & quantity/frequency substance measure	HADs access, licence and reproduction to be arranged with department Subtotal: £0
Miscellaneous	N/A	Subtotal: £0
Total		Total: <b>£132.47</b>

For any request over £200 please provide further justification for all items that contribute to a high total cost estimate. Please also provide justification if costing for an honorarium:

Trainee Signature	Date
Supervisor's Signature	Date

Appendix 3.3 – Patient Information Sheet (Version 4, 15/12/16)

## <u>Research study identifying experiences of grief in</u> <u>patients of the North West Community Addiction Team,</u> <u>Glasgow</u>

Have you had a child removed from your care by social services? Have you had someone close to you pass away?

## We invite you to take part in a research study:

Before you choose whether to take part in this study, it is important that you understand why this research is being done and what it involves. Please take time to read this information and discuss it with your clinician. It is up to you if you choose to take part. If you choose not to take part, it will not impact on any other aspects of your care. Please ask if you have any questions or want further information.

## Important things you need to know about the study:

**Who am I and why are we doing this research?** My name is Ruth Anderson. I am a Trainee Clinical Psychologist with the NHS and University of Glasgow. I am doing this research project as part of my training to be a Clinical Psychologist under supervision of Dr Lynda Russell (Clinical Psychologist, Addictions Team) and Dr Alison Jackson (Academic Supervisor, University of Glasgow).

What is the reason for this study? We want to understand more about people's experiences after a child has been removed into care or a bereavement of someone close to them.

Who can take part? The study is looking for patients of the North West Glasgow Community Addiction Team. The study is looking for parents who have had a child removed from their care by services. The study is also looking for people who have experienced bereavement. Thinking about a loved one who has passed away makes most people feel some sadness. The study is looking for participants who continue to feel highly distressed about the loss of a loved one. The study is also looking for participants who have experienced a bereavement and they no longer feel as distressed by this now. People show distress in different ways. Listed are some signs of distress to help you work out if you still feel distressed by your loss of a loved one;

- feeling tearful frequently,
- have difficulty carrying on with everyday activities,
- thinking about the loved one frequently/everyday
- experiencing lots of different feelings such as sadness, anger, shock and denial.
- looked for help from others such as your GP, your CAT worker or specialist services like Cruise.

What does the study involve? The study involves giving some general information, such as your gender, and completing three questionnaires in clinic about the person you have lost, the way you feel and your substance use. This is thought to take around 30 minutes. If you are completing the questionnaires with your Clinical Psychologist, you will complete the study during your session. If you are a client of the North West team, completing the study will take place in the waiting room prior to your usual clinic appointment because due to the busyness of the clinics there are no private rooms available. If you wish a private room, this can be arranged on request for a time out with the clinic.

**Do I have to take part in the study?** No. You do not have to take part in the study. Taking part is voluntary and you can withdraw at any time. We would like to be able to ask you for your reasons for withdrawal. You do not have to give us any reasons. We will only ask you because your answers may help us improve the way the study is carried out with other people.

Are there any disadvantages to taking part in this study? The questionnaires are of a very sensitive nature. There is a risk of you becoming distressed due to the topic of the questionnaires. You are able to withdraw from the study at any time without giving a reason if you feel it is too much for you. If you do feel distressed, the researcher and clinic team will be available at the clinic to support you. You will be given a list of supports available for you to contact if you need help once leaving the clinic.

**Are there any benefits to taking part in this study?** The findings of this study may help improve services, in particular for parents who have had a child

removed, as it will directly inform services being developed in this area currently in Glasgow.

**Will my taking part in this study be kept confidential?** Yes, all the information will be kept private with no way of identifying you. The researchers will be able to identify you so if there are any concerns from scoring your questionnaires, such as high scores, we can share this with your worker so they can help you. All information will be handled in line with the Data Protection Act.

**What will happen to the results of this study?** The results of this study will be written up as part of the main researchers Clinical Psychology training with the University of Glasgow. The team aim to try and publish the findings to share the results and inform future studies. No individual person will be identifiable when the research is published.

If you have any further questions or want to contact us further please call Ruth Anderson (Trainee Clinical Psychologist) or Dr Lynda Russell (Clinical Psychologist, Field Supervisor) on 0141 800 0670. If you wish to speak to someone independent from the project please contact Professor Rory O'Connor (University of Glasgow) on 0141 211 3920.

**What if something goes wrong?** If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions 0141 800 0670. If you remain unhappy and wish to complain formally, you can do this by contacting NHS Greater Glasgow and Clyde Complaints on 0141 201 4500.

# We are looking for people to help us with our Research Project About Grief

Are you interested in taking part in some research? We are looking for:

- Current patients of the North West Community Addictions Team
- Who have experienced one of the following
  - Parents who have had a child removed
  - o A bereavement which is causing distress
  - o A bereavement which no longer causes distress
- Distress is
  - o feeling tearful frequently,
  - o have difficulty carrying on with everyday activities,
  - o thinking about the loved one frequently/everyday
  - experiencing lots of different feelings such as sadness, anger, shock and denial.
  - looked for help from others such as your GP, your CAT worker or specialist services like Cruise.

The study involves completing an information sheet and three questionnaires in the waiting room before your usual clinic appointment. A private room can be arranged on request out with the clinic time.

If you are interested, please speak to your clinician for further information. The researcher Ruth Anderson (Trainee Clinical Psychologist) or Dr Lynda Russell (Clinical Psychologist will be present at clinic on: Appendix 3.5 – Demographic Information Sheet (Version 1 16/09/16)

## Demographic Information Sheet for Grief in an Addictions Service Research Project

Please circle your gender:

Male/Female

## **Questions about Children**

1. Have you had a child removed from your care, by social services or by your own choice?

Yes/No

- 2. How many children have you had removed from your care?
- 3. Having a child removed is a distressing and difficult time. For some people it gets easier to cope with time, but for many other people they continue to feel distressed. Listed are some common signs of distress to help you work out if you feel distressed;
  - feeling tearful frequently about the situation,
  - have difficulty carrying on with everyday activities,
  - thinking about the person frequently/everyday
  - experiencing lots of different feelings such as sadness, anger, shock and denial.
  - looked for help from others such as your GP, your CAT worker or specialist services like Cruise.

Do you continue to feel distressed by the loss of your child? Yes/No

## **Questions about Bereavement**

1. Have you experienced the bereavement/death of someone close to you?

Yes/No

- 2. How long ago did they pass away? \_\_\_\_\_(years & months)
- 3. The death of someone close to us is difficult and distressing. For some people it gets easier to cope with time, but for many other people they continue to feel distressed. Listed are some common signs of distress to help you work out if you feel distressed;
  - feeling tearful frequently about the situation,
  - have difficulty carrying on with everyday activities,
  - thinking about the person frequently/everyday
  - experiencing lots of different feelings such as sadness, anger, shock and denial.
  - looked for help from others such as your GP, your CAT worker or specialist services like Cruise.

Do you continue to feel distressed by the bereavement?

Yes/No

## Appendix 3.6 – Grief Cognition Questionnaire (Version 1 16/09/16)

Questionnaire removed as not owned by author.

## Appendix 3.6 cont - Adapted Grief Cognition Questionnaire for Birthparents Who Have Had a Child Removed from their Care (Version 1 16/09/16)

Questionnaire removed as not owned by author.

## Appendix 3.7 – Hospital Anxiety and Depression Scale (HADS)

Questionnaire removed due to copyright.

## Appendix 3.8 – Substance Misuse Measure (Version 1, 16/09/16)

## Measure of Substance Use

For each substance, please tick if you use it, how often and write how much.

	Daily	Weekly	Monthly	Yearly	If yes, how much?
Alcohol					
Heroin					
Benzodiazepines					
Cannabis					
Cocaine					
Crack cocaine					
Amphetamine (Speed)					
Ecstasy					
Ketamine					
Acid/LSD					
New Psychoactive Substances (Legal Highs) e.g. Methadrone					

If you are **not** using any substances current, what substances did you use in the past?

Are you on any replacement regimes? e.g. methadone/naltrexone/antabuse? (please circle) Yes/No

If yes, what? \_\_\_\_\_

# <u>Consent Form</u> <u>Participants Copy</u>

## Research study identifying experiences of grief in patients of the North West Community Addiction Team, Glasgow

If you are interested in taking part in the study, please initial to confirm you understand the following:

## Initials

I have read and understood the information sheet titled '*Research* study identifying experiences of grief in patients of the North West Community Addiction Team, Glasgow'. I have had the opportunity to ask the researcher any questions I have.

I understand that I can stop completing the questionnaires at any time. If I do, my information will not be used as part of the project.

My on going care from the Addictions Team will not be affected if I choose not to take part.

I understand that any clinical concerns from the questionnaires will be shared with my worker.

If you are happy to take part in this project, please sign below:

I\_\_\_\_\_ (write your name) consent to taking part in the research project exploring experiences of grief in the Glasgow Addictions Service.

Signed\_\_\_\_\_

Date\_\_\_\_

Consent taken by:

Clinician Name\_\_\_\_\_ Signed\_\_\_\_\_

Designation	
Date	

# <u>Consent Form</u> <u>Researchers Copy</u>

## Research study identifying experiences of grief in patients of the North West Community Addiction Team, Glasgow

If you are interested in taking part in the study, please tick to confirm you understand the following:

Tick

I have read and understood the information sheet titled '*Research* study identifying experiences of grief in patients of the North West Addiction Service, Glasgow'. I have had the opportunity to ask the researcher any questions I have.

I understand that I can stop completing the questionnaires at any time. If I do, my information will not be used as part of the project.

My on going care from the Addictions Team will not be affected if I choose not to take part.

I understand that any clinical concerns from the questionnaires will be shared with my worker.

If you are happy to take part in this project, please sign below:

I\_\_\_\_\_ (write your name) consent to taking part in the research project exploring experiences of grief in the Glasgow Addictions Service.

Signed\_\_\_\_\_

Date\_\_\_\_

Consent taken by:

Clinician Name\_\_\_\_\_

Signed\_\_\_\_\_

Designation\_\_\_\_\_

Date\_\_\_\_\_

## Appendix 3.10 – Support Services Information Sheet (Version 2, 15/12/16)

## **Support Services and Helpline Numbers for Addictions Service**

If you need support and advice during normal working hours (Mon-Fri 9am-5pm), contact your addictions worker on their usual number. The main Community Addiction's Team office numbers are: Possilpark Health and Care Centre – **0141 800 0670** Closeburn Street – **0141 276 4580** Hecla Street – **0141 276 4330**.

For out of hours medical advice, contact NHS 24 on **111**.

If it is an emergency, contact the emergency services on **999**. Attend A&E yourself if you are able to do so.

## **Support Services For Mental Health:**

## Samaritans 116 123

Space to talk about how you are feeling. Free to call. 24 hours a day, 365 days a year.

## Breathing Space 0800 83 85 87

Space to talk about how you are feeling. Free to call. 24hours at weekends (6pm Friday – 6am Monday) Monday – Thursday (6pm – 2am)

# Support Services for Alcohol and Drugs:

## Drinkline 0300 123 1110

For support with your alcohol use. Free to call. Weekends 11am – 4pm Weekdays 9am – 8pm

## Alcoholics Anonymous 0800 9177 650

For support with alcohol problems (free to call)

# Narcotics Anonymous 0300 999 1212

For support with drug problems, daily from 10am to midnight. Free to call.