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An exploration of the experiences of support for informal adult carers of individuals with substance use issues in North East Scotland.

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2019

An exploration of the experiences of support for informal adult carers of individuals with substance use issues in North East Scotland

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Declaration

I hereby declare that I conducted all the work represented in this thesis entitled: An exploration of the experiences of support for informal adult carers of individuals with substance use issues in North East Scotland. No part of this has been accepted in any previous application for a degree. All quotation marks and their sources are acknowledged.

Mary Munro

30th October 2019

“It’s always time to question what has become standard and established”

David Bowie

Abstract

Background: Informal carers provide unpaid support to an individual, usually a family member. The care and support which they provide has been shown to provide positive effects to the individual they support. However, this role may impact on the informal carer, often on their psychosocial wellbeing. Although there have been efforts to address the needs and experiences of informal carers as a population group in general, little research has been conducted to explore the experiences of informal carers of individuals with substance use issues.

Rationale: Substance use issues have increasingly become a focus for public health and government policy in the United Kingdom (UK). Informal carers provide support to over one million individuals with substance use issues every day. Therefore, the aim of this thesis is to illuminate the experiences of informal carers with a focus on their experiences of support services, and their preferences for support.

Method: Eight qualitative semi-structured interviews with informal carers were conducted between May 2018 to July 2018 to explore and understand their role and experiences of support they receive. Thematic analysis was conducted to illuminate the experiences of support for the participants.

Findings: Informal carers described both positive and negative experiences from their caring role. They described that often there was little to no choice in becoming an informal carer, and often no support. No informal carers were offered any form of carers assessment, nor were they offered any practical support such as financial aid or respite. The informal carers role often left participants feeling lonely and isolative. Specific carer groups for individuals with substance use were deemed to be helpful, as this allowed individuals to discuss their situations, feelings and experiences with others who understood and had similar experiences.

Conclusion: Informal carers move from informal to formal support often over a long period of time as they come to terms with the substance use issues of their loved one and usually at a point of crisis. Informal carers in this study reported the need to feel understood in relation to their feelings of being valued in their caring role, included in discussions and decisions and importantly, that they were not judged by others.

Keywords: Informal Adult Carers, Substance Use, Substance Misuse, Carers, Caregivers, Family Caregivers, Addiction, Drug Use

Abbreviations used within thesis

ADA	Alcohol and Drugs Action
AFM	Affected Family Member
Al-Anon	Alcoholics Anonymous
AXIS	Appraisal tool for Cross-Sectional Studies
BI	Brief Intervention
CASP	Critical Appraisal Skills Programme
CPN	Community Psychiatric Nurse
CSNAT	The Carer Support Needs Assessment Tool
FM	Family Member
GCP	Good Clinical Practice
GP	General Practitioner
IDU	Injecting Drug User
MMAT	Mixed Methods Appraisal Tool
NHS	National Health Service
NICE	National Institute of Clinical Excellence (NICE)
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Control Trial
R&D	Research and Development
SIGN	Scottish Intercollegiate Guidelines Network
SUD	Substance Use Disorder
UK	United Kingdom
USA	Unites States of America
WHO	World Health Organisation

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CHAPTER ONE: INTRODUCTION AND BACKGROUND TO STUDY

1.0 Introduction

This chapter introduces the reader to the purpose and subject matter of this thesis. A brief overview of substance misuse issues and informal carers are provided to inform the reader about the context of the study. Clarification of the researcher's own personal position is presented and an overview of the structure of the thesis.

1.1 Outline of the thesis

This thesis is structured into five chapters. This first chapter introduces the thesis. The systematic literature review is presented in chapter two. Chapter three focuses on the methods and methodology adopted for this thesis. The main themes derived from the data are presented in chapter four. Finally, in chapter five the findings from the study are discussed, the limitations and strengths are identified alongside the study's contribution to knowledge. This chapter concludes with recommendations for policy, clinical practice and future research.

1.2 Background to study

Substance misuse can often be described as hidden in nature, which may mean that there are a large number of individuals affected by substance misuse unknown to care services (Velleman et al. 2008, MacMaster 2008, Biegel et al 2007). Furthermore, the hidden nature of substance misuse means that the evidence available about individuals supporting this population group is limited (Scottish Families Affected by Drugs and Alcohol 2017).

In 2007-2008, the public sector spent £173 million on drug and alcohol services in Scotland, with £84 million specifically on drug services, £30 million on alcohol services and the remainder was spent on joint drug and alcohol services (The Scottish Government 2016). The prevalence and consequences associated with substance misuse issues have been not only a national concern but also a global one (World Health Organisation [WHO] 2014). It is estimated that five percent of the global burden of disease is associated with alcohol use (WHO 2014) and there is worldwide concern over the rise in opioid overdoses (Global Drug Survey 2015). In the United States in 2016, there were 42,249 opioid drug overdose deaths (The Office of Disease Prevention and Health Promotion 2017). At a national level, it was reported that there were 1187 drug overdose-related deaths in Scotland in 2018, the highest ever recorded (The Scottish Drugs Forum 2019).

A clear definition of substance misuse is needed for the use in theory, research and practice (Kelly, Wakeman & Saitz 2015). The term substance misuse can be defined as the overuse of drugs in a harmful or hazardous way (i.e. analgesics, tranquillisers, sedatives, alcohol and stimulants) and as a result, the term substance misuse has been used to describe a broad range of substances (Kelly, Wakeman & Saitz 2016). For this study, it was necessary to avoid negative or stigmatising terminology. Therefore, the definition stated above for substance misuse, an individual with substance use disorders (SUD's) or substance use issues will be used. It was judged that these terms would be the most appropriate for this research study as there were no limitations on the type or severity of substances used by the individual experiencing substance misuse issues.

1.3 Informal carers

It is estimated that there are currently 1.4 million support persons for individuals experiencing SUD's in the UK and that one in twenty households have experienced addiction in their family at some point (Scottish Families Affected by Alcohol and Drugs 2017). This figure is believed to be an underestimate because individuals may not access support due to barriers to access services and other factors such as stigma or embarrassment (The United Kingdom (UK) Drugs Policy Commission 2012). Currently, the Scottish Government has published guidance on policies to help aid harm reduction and recovery-focused care for individuals experiencing substance use disorders (The Scottish Government 2013). However, the recommendations have not been introduced in policy or practice within health and social care organisations to meet the needs of a support person of someone with SUD's. Providing appropriate support for support persons could improve health and wellbeing outcomes for not only the carer themselves but also the individual/s that they are caring for (The UK Drugs Policy Commission 2012). The value of the care and support provided to individuals with SUD's by support persons is estimated to be £3,935 per family member per annum. Therefore, the total annual saving to statutory services for the UK is estimated to be £750 million (The Scottish Government 2018).

The UK Drugs Policy Commission (2012) identified that 250,000 individuals are severely affected by a relative's problematic use of opiates or crack cocaine. It is estimated that 130,000 people have a relative who shows signs of dependence on cocaine powder and over one million people have a relative who shows signs of dependence on cannabis. There are currently no data available on the estimated number of individuals supporting someone with alcohol misuse. The UK Drugs Policy Commission (2012) study highlighted that 575,000 individuals were spouses, 610,000 were parents, and 250,000 are other family members, such as grandparents or siblings, in the support person role. Furthermore, over 140,000 family members are living with someone who is receiving treatment for illicit drug use. These figures are minimum estimates but demonstrate the enormous impact of drug use and identifies the potential unmet needs for this huge population of support persons. These findings underscore the importance of identifying and supporting this often-unrecognised or 'hidden' group of individuals. People with substance misuse issues however isolated, will have networks of families and friends who will feel the impact of drug and alcohol issues, whether they have become estranged or continue to provide vital support (ADFAM 2017). Support persons are frequently an unrecognised, unappreciated and unpaid resource providing economic and other forms of support to the individuals who they support (Scottish Families Affected by Alcohol and Drugs 2017).

On the 1st April 2018, The Scottish Government (2018) Carers (Scotland) Act (2016) came into effect. This Act enhances the rights of carers in Scotland and aims to help improve carers overall wellbeing so that they can continue to care, if they wish, and support them to have independence alongside the caring role. There are three critical legislative drivers who have significantly changed how we should work with adult carers within Scotland and these include: The Carers (Scotland) Act (2016), The Scottish Government Public Bodies (Joint Working) (Scotland) Act (2014) and The Scottish Government (2013) Social Care (Self-directed Support) (Scotland). The main aim of the Carers (Scotland) Act (2016) is to highlight a focus on assessing the needs of the carer separately from the needs of the cared-for individual. The involvement of family members in treatment is still only considered as guidance (National Institute of Clinical Excellence (NICE) 2017). Furthermore, despite a range of policy-based relevant publications at grassroots, there remains a disparity in the delivery of family inclusive services across Scotland (The Scottish Government 2016). Recent published clinical guidelines NICE (2017) and the Shared Care Scotland Carers Bill (2017) highlighted that all informal carers should have access to an individual need's assessment, social and practical support, such as respite, including individuals supporting people with substance misuse issues.

The Carers (Scotland) Act (2016) defines a 'carer' as an individual who provides or intends to provide care for another individual. The term 'carer' has often been defined in terms of the physical activities required to support an individual with a condition. These caring duties include providing personal care and administration and monitoring of medications (Anderson 2017). In the context of this current study it is important to distinguish that the traditional carer definition may not be appropriate to use. Often the caring role for individuals with substance misuse does not necessarily require offering support with physical activities as identified within the literature. Moreover, some individuals may not actually identify themselves as a 'carer', but rather they have adapted their mentality to 'It's just something you do'. Some individuals have highlighted that they are first and foremost a husband, wife, son, daughter, or friend, which perhaps sometimes this role can be seen as a duty for their loved one (Copello, Templeton and Velleman 2006, Li et al. 2014, Sakiyama et al. 2014, Vellman et al. 2008, Templeton 2009). Given these important considerations and to help aid with the recruitment process of participants in this study, the term 'support person' has been adopted in this thesis. Support person refers to an individual close to the individual experiencing substance misuse issues providing support.

A support person can provide care from anything from a few hours a week, to 24 hours a day seven days a week and the care they provide can be 'light touch' or 'intensive' (Carers Trust 2012). Being a support person for an individual with substance use issues can often mean supporting the individual with their substance use but can also mean helping them with their mental health, known as dual diagnosis. Dual diagnosis is the term used when a person has a mood disorder such as depression or bipolar disorder and a problem with alcohol and/or drugs (Subodh, Sharma & Shah 2018). Supporting an individual with a dual diagnosis can be difficult as substance misuse and mental health can be unpredictable at times (Skogens, Greiff & Topor 2018).

The Scottish Government (2010) produced the Carers Strategy (2010-2015) a 'Best Practice Framework' with local eligibility criteria for unpaid support persons. This strategy has identified seven areas of a support person's life which may be impacted: health and wellbeing, relationships, finance, future planning, life balance, employment and training and the environment. At a local level, Aberdeen City Health and Social Care Partnership (2018) have adopted this framework to help determine their eligibility criteria for assistance for support persons. The partnership considers each area of impact, with the aim to have a comprehensive assessment of a support persons needs and to begin to identify appropriate support to help minimise any potential negative effects of their caring role. Each of the seven areas may not be relevant for all support persons and not every support person will be affected to the same degree, but nevertheless, it is important that all areas are considered in all circumstances for each individual.

The impact that being a support person for an individual with substance misuse issues has on their health & wellbeing is documented within previous research (Sakiyama et al 2014, Copello et al 2009; Biegel et al 2007; Silver 1999). A focus on psychosocial health has become a key element in the care and treatment of patients within mental health and substance misuse services (Trenoweth & Moone 2017). Four key areas which can influence an individual's overall wellbeing are their mental, emotional, social and spiritual health. Within mental health practice it has been well established that a balance across all the four elements are essential for positive wellbeing to be attained (Pinquart & Sorensen 2006).

Supporting an individual with substance misuse issues can often be upsetting if the person is physically or mentally unwell or if there is unpredictability and challenging behaviours. A change in behaviour can affect the support person's emotions, and in some cases, they can experience feelings of bereavement (Manthope, Moriatry & Cornes 2015). The support role can affect the support person's ability to work which may affect their finances. If the individual they are caring for was the main household earner and their condition has meant that they have had to give up paid employment, this may add to significant stress for the household and family (Biegel et al 2007). Often support persons put the needs of the cared-for person first and don not have the time to fully consider their own needs, leading to these being neglected (Velleman et al. 2008, MacMaster 2008). In some situations, it can be difficult for the support person to make any future plan. Planning for the future can be stressful in any area of their life from their career, their education and development, or even their social life. They may be forced to delay starting work or training, give up work or a course, take early retirement or reduce their working hours as a result of their supporting role (Copello 2002).

1.4 Study rationale

Despite the recent change in policy and clinical guidelines (NICE 2014) and Carers (Scotland) Act (2016) currently little is known about what support is being provided for support persons of individuals with SUD's. This is the overall aim of this study and these findings illuminate the participant's experiences of support. These findings have the potential to inform future developments for service delivery, better inform policy and provide services with a better understanding of the support needs of support persons of individuals with SUD's.

1.5 Researchers perspective

In my first post as a registered mental health nurse I gained experience in forensic mental health services in an inpatient hospital setting. A large percentage of the patients who I had contact with not only had a mental health diagnosis but also had some form of SUD. I found this exposure to clinical practice fascinating and challenging. This environment allowed me the opportunity to fuel my passion and identify my niche for working in the field of substance use. While working in this environment, I had a chance to work closely with family members and gain a perspective on their needs and what was involved within their caring role.

I then moved from an inpatient hospital setting to a community mental health nursing role within substance misuse services. The knowledge, skills and experience I gained during my time in the inpatient environment allowed me the opportunity to transfer these skills and expertise to the community setting and work exclusively with patients, families and carers in this specialist setting. During my time working within the substance misuse services, I became more aware of the negative impact being a support person for someone with substance misuse issues may have on their wellbeing. Therefore, I began to question if there were services to provide appropriate support for the support person in their own right. Consequently, my own experiences of working in this environment provided my interest and motivation to take forward this subject for further enquiry.

1.6 Study set up

This study began in October 2017. During the first four months, I prepared my research for submission to Robert Gordon University ethics committee and completed a postgraduate module in research methods. I spent time developing relationships with organisations which I could potentially recruit participants from, including third party substance misuse and carer organisations. I made contact via email and telephone conversations initially and then met with representatives in these organisations face-to-face to discuss the aims and objectives of my study with staff members, who later identified if they would be willing to participate. Two out of the five organisations I approached agreed to support my study. The organisations I made initial contact with were Alcohol and Drugs Action, Voluntary Service Aberdeen, Voluntary Service Aberdeen Royal Cornhill Hospital, AIR Aberdeen and Al-anon (Alcoholics Anonymous). Overall, I found my time with these organisations and their reaction to my thesis to be positive. It helped me to consider my role as a researcher rather than a clinician and clarify what was possible within the available time and resources of this study. Initially, there were some questions regarding how the outcomes would impact their service and some individuals thought that this might have a negative impact if some of the findings would identify specific experiences or services as being negative. After discussions with each organisation it was agreed that the study and experiences of the support persons would aim to help to identify the positives of services, but also if there were negative experiences, then these could be used to inform future developments for service delivery.

1.7 Summary

Support persons play a valuable part in the care and treatment of an individual with substance use issues. They have been referred to as ‘hidden’ and ‘forgotten’ individuals within local and national policies, highlighting that more needs to be done to recognise the contribution of care which they provide. However, there should be a focus on how their supporting role may have an impact on their own wellbeing. The next chapter of this thesis will present the integrative literature review findings and seeks to appraise what support is currently being implemented for support persons supporting individuals with substance misuse issues and inform the research questions for this thesis.

CHAPTER TWO: LITERATURE REVIEW

2.0 Abstract

Background: For those caring for an individual dependent on drugs or alcohol, support services can be variable. Research to date, appears to identify what impact the support person has on the individual using drugs/alcohol rather than the impact that this may have on the support person. There is a policy requirement for health services to deliver care and support to informal adult carers with a growing emphasis on the need to address their own preferences for support.

Aim: The aim of this literature review was to identify what support, support person's access and to distinguish what impact the role has on their psychosocial wellbeing.

Method: An electronic search was conducted between 1st October 2017 and June 2019 using key search terms. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to conduct this review. Primary research studies were quality appraised using Critical Appraisal Skills Programme (CASP), Appraisal tool for Cross-Sectional Studies (AXIS) and Mixed Methods Appraisal Tool (MMAT).

Findings: 13 papers were included in this review and the findings were developed into three overarching themes entitled, 'carer profile – who support persons are', with two sub-themes – 'carer characteristics' and 'understanding the term carer'. The second overarching theme was 'support for support persons' with three sub themes: 'Support being offered', 'support for the support person' and 'preferences for support'. The third and final theme was 'effect on psychosocial wellbeing'. The literature search identified the demographic characteristics are represented in this population group and highlighted key support which support persons find helpful. Furthermore, the findings identified why individuals may not access support, and added valuable insight into the negative consequences of the support person role.

Conclusion: This review identified what support is currently available for support persons of individuals with substance misuse issues. Furthermore, it has highlighted the demographics

of who makes up this caring group, the psychosocial impacts of the role and support persons preferences for support. Importantly, this review has demonstrated that most of the body of research which has been conducted in this clinical area is quantitative in design, so the experiences of support persons are relatively unexplored. Therefore, this underscores an important gap and the need to conduct qualitative research to understand informal adult carers experiences and needs for support from their perspective.

2.1 Literature review introduction

This chapter presents a synthesis of the current evidence from published qualitative and quantitative studies on support persons of individuals with substance misuse issues. Relevant studies were identified and appraised, and the findings of the primary studies were thematically analysed using integrative review methodology. This systematic approach to the review informed the aims and objectives of this study in order to contribute to knowledge in this area. The integrative review questions were developed to help guide the review and are displayed below:

1. What service support exists for support persons supporting individuals with substance misuse issues?

2. What is the impact on psychosocial wellbeing for support persons?

3. What preferences for support do support persons have, and are these preferences being met?

2.2 Objectives of this chapter

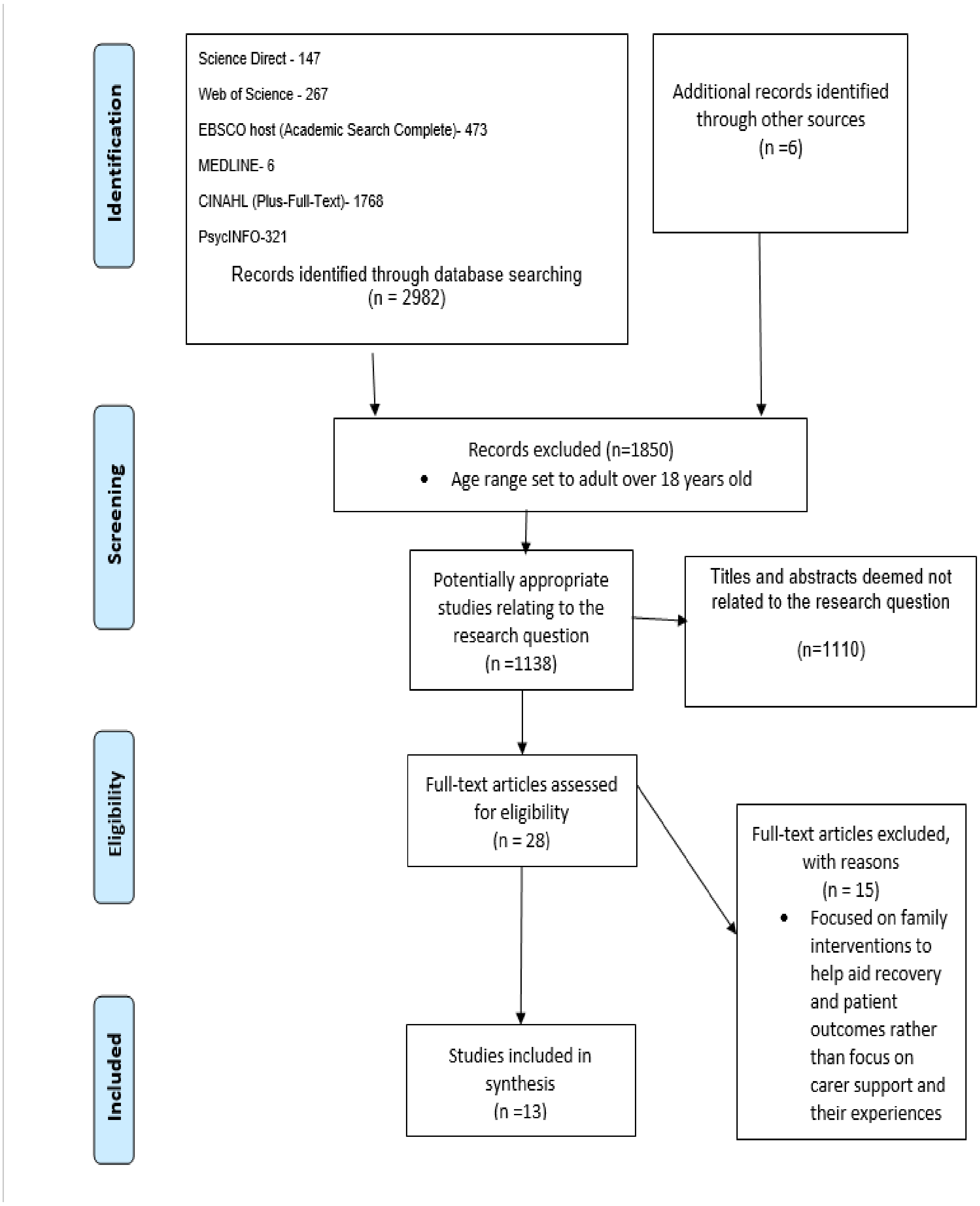
The following objectives set to guide the integrative review chapter are:

- Search for primary research published from 1993 to June 2019,
- Complete primary data extraction from the included studies,
- Assess the methodological quality of the included studies,
- Identify support for support persons of individuals with substance misuse issues within the empirical literature,
- Synthesis of the findings of the included studies to give an international perspective on what support is available, and what the effect of the role of the support person has on their psychosocial wellbeing.

2.3 Search strategy

The initial stages of the research study included a scoping exercise of published empirical material relating to support persons of individuals with substance misuse issues to ascertain what is already known in this area. A review protocol was developed and published in Prospero (Munro, Paterson & Kennedy 2018) available from https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=80062. This protocol informed the conduct of this integrative literature review which was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (2015) statement guidelines detailed in Figure one. Table one provides information on the database search strategy and inclusion and exclusion criteria.

2.4 Figure one- Prisma flowchart



2.5 Table One: Databases, search terms, inclusion/exclusion criteria of the literature review

Literature searched from 1993- 2019
Databases searched during time period: 1st October 2017 –20 June 2019
Cochrane Database of Systematic Reviews Science Direct Web of Science EBSCO host (Academic Search Complete) MEDLINE CINAHL (Plus Full-Text) PsycINFO PsycARTICLES Websites of the National Service User Executive The Care Quality Commission and National Health Service (NHS) Hand searching of key reference lists
Key search terms
Support persons, support person, support, informal adult carers, carers, caregivers, adult carers, families, family centred, affected family members, affected members of the family, lived experience, living with, substance misuse, substance use, drug use, alcohol use, alcohol abuse, drug abuse, substance use disorders, substance abuse, drug and alcohol use, health care, social care, psychosocial support, psychosocial, alcohol/drug dependence/addiction, qualitative, mixed methods and quantitative research
Inclusion criteria
Inclusion criteria were support persons of people affected by substance use, over the age of 18 years old, studies published in the English language, peer-reviewed qualitative and quantitative studies, and studies with a focus on supporting support persons of people with substance use issues.
Exclusion Criteria
Research which explored support for individual who uses substances. Research that explored the experiences of persons under the age of 18.

An example of the search strategy is provided in appendix one. Reference lists of included papers were reviewed for additional studies, eliciting six further papers. All titles and abstracts were reviewed using a pro-forma checklist to make decisions to include or not to include studies, based on the inclusion criteria. All articles which met the inclusion criteria were retrieved in full-text. Any disagreements were resolved through discussion between my supervisors and myself. Data extraction tables were developed (shown in Appendix two) as this helped to identify critical points in each paper and the analysis of data to illuminate themes and address the research questions.

Data were extracted from the included studies, and my supervisors then verified this process as part of quality assurance. The included studies were subject to a quality appraisal using quality appraisal tools. Quantitative and qualitative studies were assessed using the checklists provided by the Critical Appraisal Skills Programme (CASP) (2017), Appraisal tool for Cross-Sectional Studies (AXIS) (2016) and mixed methods using the Mixed Methods Appraisal Tool (MMAT) (2018). Examples are provided in Appendix three, four, five, six and seven. Each full-text paper was read several times before quality appraisal and data extraction. Papers were not excluded based on their quality assessment but rather the purpose of the quality appraisal was to allow overall conclusions to be drawn about the quality of current evidence. Whittemore and Knafl (2005) highlight the difficulty of quality appraisal in integrative reviews, as studies with different research designs are often included in one review.

2.6 Literature review results

Of the 2982 literature hits identified from the search 2969 papers were excluded as they did not meet the inclusion criteria (see table one). In total, 13 articles were included in this integrative review. Most of the studies were conducted in the United Kingdom (n=6) and the United States of America (n=3). The remainder of the studies were conducted in Vietnam (n=1), Canada (n=1), Italy (n=1) and Brazil (n=1). The included studies used a range of qualitative and quantitative approaches and included: feasibility studies (n=3) Templeton (2009), Velleman et al (2008), Biegel et al (2007), non–experimental cross-sectional surveys (n=3), Slaunwhite et al (2017), Sakiyama et al (2014) and MacMaster (2008), randomised control trials (n=3), Li et al (2014), Velleman et al (2011) and Copello et al (2008). There were three qualitative studies (n=3) Manthorpe, Moriarty & Cornes (2015), Orr, Barbour & Elliot (2012) and Ritcher, Chatterji & Pierce (2000), and mixed methods studies (n=1), Velleman et al (1993). Participant recruitment in the studies varied between eleven and one hundred and forty-five, in total there was (n=804) participants across the included studies.

2.7 Critical appraisal tool limitations

There are some limitations to the findings of this review. Firstly, only English language papers were included, which may limit the findings of this review internationally. However, this review did include a range of papers conducted globally which is a strength. Secondly, it is important to recognise the different healthcare systems, policies and cultural differences across the international evidence-base. Findings from this review have highlighted significant issues for support persons experience including negative psychosocial wellbeing, with a particular focus on their emotional wellbeing. Of the interventions conducted in this area, there was little scientific justification for why a specific intervention such as the five-step brief intervention (Copello et al. 2009) was selected. As an important clinical consideration, the intervention studies did not report why a particular method was used with the chosen population group, or why a particular intervention had been adopted for the study (Li et al. 2014, Sakiyama et al. 2014, Templeton 2009, Vellman et al. 2008).

Further limitations of the studies identified through the CASP (2017) and MMAT (2018) tool were, the sample sizes were small, and the follow-up period was short; therefore, the study results did not provide conclusive evidence of the efficacy of the intervention in the following studies (Li et al 2014, Ritcher, Chatterji & Pierce 2000 and Templeton 2009). All studies further highlighted a limitation in the results that it is possible that the data collected are biased towards family members who are more stable, at least in terms of engaging with a service. Furthermore, it could be suggested that those individuals consenting to take part may be more motivated or satisfied with the support they receive, therefore may not have been an overall representation of the study group as a whole.

2. 8 Analysis

Data were extracted using a predetermined format which included the studies aims, objectives, methodology and key findings of the 13 included papers. A thematic analysis of the data was completed following Braun and Clarke (2012) thematical analysis framework. The trustworthiness of the analysis was enhanced by review and dialogue around the emerging analysis and interpretation with my supervisors throughout all stages of the literature search, data extraction, analysis and presentation of findings.

2. 9 Themes

There were several themes which were identified from this review of the literature (detailed in table two). Once data had been extracted, I then started to develop themes in a separate word document to identify commonalities and differences between the included studies. The first theme was entitled, ‘Carer Profile – who support persons are’ which was developed to provide better insight into who are the support persons of individuals with SUD’s. The first sub-theme was entitled as ‘carer characteristics. When extracting data from the carer demographics, I extracted data about the participant’s sex, age, and length of time that a participant had been a support person for. To gain an understanding about the clinical context in regard to the terminology of ‘support persons’, I then extracted data from each paper where the authors provided their own definition of who constitutes as a support person. The second sub-theme ‘Understanding the term carer’ was valuable to inform my research going forward as it developed an insight into the different demographic characteristics of this clinical group to inform my recruitment strategy of my main research.

The second overarching theme which emerged was related to ‘Support for the support persons’ identified what support services support persons access. The first sub-theme was entitled ‘support being offered’ which explored what type of support was being offered to the participants, if any. The second sub-theme ‘preferences for support’ explored what participant’s preferences for support were articulated, and to what extent their preferences were being met. The final overall arching theme was titled ‘effect on psychosocial wellbeing’. It became apparent most studies tended to focus on the negative consequences associated with being a support person.

2.10 Table two: Themes

Theme	Sub-Theme
Carer profile – who support persons are	Carer characteristics Understanding the term “Carer”
Support for support persons	Support being offered Preferences for support
Effect on psychosocial wellbeing	

2.11 Carer profile

As presented in chapter one, little is known about support persons of individuals with SUD’s. Therefore, an important outcome was to build a picture of what is already known about who this group of individuals are to identify the demographic profile and synthetize their commonalities and differences.

2.12 Carer characteristics

In MacMaster’s (2008) study 110 respondents were interviewed on their experience of being a support person. Out of the 110 respondents, 76% (n=83/110) were parents and 72% (n=79/110) were female, with the average age of the support person being 60 years old. This was comparable with Li et al’s (2014) study who recruited 83 family members of injecting drug users (IDU’s) of which 81% (n=67/83) were female. Spouses represented 40% (n=33/83) of the respondent’s relationships, 33% (n=27/83) were parents and 12% (n=10/83) were siblings and the remaining percent were other family members and friends. However, this study did not breakdown specific family roles. The figures were further supported in a Scottish context by the work of Orr, Barbour & Elliot’s (2012) study. Twenty participants were interviewed, with 18 being parents 90% (n=18/20), 1 an aunt and 1 a sister. Nineteen respondents were female, and 1 was male with the average age of the respondents being reported as 42 years old, which was considerably less than Macmaster’s (2008) study.

Furthermore, in Velleman et al's (2008) study they recruited 143 family members. The demographics identified 85% (n=121) of the family members were female, 52% were partners (n=74), 35% were parents (n=50), 6% were adult children (n=8) and 7% were other family members (n=10), although the authors did not report what the other family member roles were compromised of. The mean age of the time spent being a support person was 9 years. Furthermore, in Copello et al's (2008) study they interviewed fifty- two family members. Again, 90% were female (n=47/52) with a mean age of 46 years old. Most individuals were mothers (40%), and female partners (38%). The remainder of the participant group were sisters, daughters and a very small percentage were male. Sakiyama et al (2014) further identified that females provided the majority of the support person's role. Fifty respondents were recruited highlighting that 68% were parents (n=30/50), 11% marital partner (n=5/50) and 9% siblings (n=4/50). A small percentage (4%) indicated that they were grandparents (n=2/50) and 8% partners or friends (n=4/50).

Biegel et al's (2007) recruited eighty-two respondents differed from all other included studies in that 40% of support persons were male. Almost one third 31% (n=25/82) of the caregivers were the significant other of the care recipients, with the remaining respondents' siblings 23% (n=18/82), parents 19% (n=16/82), child 11% (n=9/82) and other relative 15% (n=12/82). The mean age remained comparable to other studies with a mean age of 40 years old. Velleman et al (1993) interviewed 50 family members affected by substance use. 56% (n=28/50) were partners (19 female and 9 male), 38% were parents (n=19/50),11 mothers and 8 fathers and 6% (n=3/50) were 3 other family members (1 sister, 1 brother and 1 daughter). Parents had on average five years of exposure to drug use and partners had an average exposure of nine years.

In Richter, Chatterji and Piece's (2000) study investigating eleven Alcoholic Anonymous (Al Alnon) participants were interviewed, however it did not provide specific characteristic figures and only stated the respondents were mostly female of middle age who were spouses of the individual they provided care for. Noteworthy, there were no characteristics available for Manthorpe, Moriarty & Cornes (2015) study's.

These studies provided an insight into the characteristics of a support person of an individual with SUD's in existing studies in this area. The included studies provided an important international context and were conducted in Brazil, Italy, Vietnam, America, Canada and the United Kingdom, yet the main support person was female across all of the studies. Furthermore, most participants were parents, closely followed by spouses or partners. The age of the support person averaged between 40 years and 60 years old. Important to note men were significantly unrepresented in all studies except in Biegel et al (2007), although the reasons for higher rates of male participation in this study are unclear. This theme has provided insight into who makes up this population of support persons. Evidence has shown that the existing studies in this area are females between the age of 40-60, who are generally a mother or spouse. However, what is not clear from any of the literature is how or why they acquired these supporting roles compared with other members in the family unit.

2.13 Understanding the term 'carer'

Across the 13 studies the term 'support person' was not used. In the literature search, there were no results for the term 'support person'. It was evident that the use of the terminology to describe a support person differed across countries. In the American and Canadian studies, the term used to describe a support person was the 'affected family member', 'care provider' and 'caregiver' (Slaunwhite et al 2017, Biegel et al 2007). In the studies conducted in the United Kingdom, the term 'caregiver' or 'carer' was used (Manthorpe, Moriarty & Cornes 2015 and Orr, Barbour & Elliot 2012). In the remaining studies Li et al (2014), Sakiyama et al (2014), Velleman et al (2011), Copello et al (2009), Tempelton (2009), MacMaster (2008), Velleman et al (2008), Ritcher, Chatterji & Pierce (2000) and Velleman et al (1993) the authors did not define or mention the terms adult carer or support person but instead they explored the experiences of 'family members' or 'affected family members'.

Only one study explored the meaning of the term 'adult carer' with the participants themselves across the included studies (Orr, Barbour & Elliot 2012). In the Orr, Barbour & Elliot (2012) study only half (n=9/18) of the eighteen participants identified themselves as a 'carer' and related this term to providing physical and emotional support due to being heavily involved in caring for their dependent children. Eight participants (n=8/18) did not define themselves as a 'carer' at all, but rather adopted the mind set of being a family member and 'doing what a family member has to do'. Knowles et al (2016) highlighted that the term 'carer' can often be difficult for individuals to adapt to and relate to which is reflected throughout the majority of healthcare research.

Orr, Barbour & Elliot (2012) further identified that participants perceived that caring for someone with substance use issues was less predictable and more isolating than other carer groups, such as caring for individuals with a physical illness or disability but did not provide details as to why. Furthermore, in Orr, Barbour & Elliot's study (2012) participants agreed that they perceived their carer role to be different to other carer groups. They perceived that there would be more support available, less judgement, or blame towards the support person caring for an individual with a long-term condition such as cancer, or heart disease. Manthorpe, Moriarty & Cornes (2015) reinforce these findings in their study. Several participants in the study felt that society had a clear vision of what a ‘carer is’. The participants reported that this ‘view’ of a carer would be a person who looked after an individual with a disability, and substance use did not fall into this category. Another finding suggested that participants may not have wanted to identify as a support person or ‘carer’ or actively seek support, due to the social stigma attached to substance use issues.

The definition of a support person was not used to define informal adult carers. Researchers adopted a variation of different terms, which appeared to differ dependent on geographical location of where the studies were conducted. This information provides insight into how different countries may recruit the same population group with different terms. In the context of what ‘carer’ meant, only two studies Orr, Barbour & Elliot (2012) and Manthorpe, Moriarty & Cornes (2015) investigated what this meant to the participants. From the papers who did mention what this term meant to them, there appeared to be commonalities within the studies. The first being the identification of a ‘carer’ itself. Some participants did not necessarily identify as a ‘carer’ Orr, Barbour & Elliot (2012) but rather an adapted role, and ‘just something you do’ Manthorpe, Moriarty & Cornes (2015) as a partner or parent. The second commonality identified that some participants felt that they may not self-identify as a carer, but also some individuals in society may not view them as a carer. This was due to society’s perception that a carer tends to be caring for an individual who has a disability or physical condition (Manthorpe, Moriarty & Cornes 2015, Orr, Barbour & Elliot 2012 and Velleman et al 2011). Due to this perception that their role was different to other caring roles, participants described that they felt that their caring role was not as recognised as other caring groups, and therefore felt that they received less support and more judgmental attitudes.

2.14 Support for the support person

The reasons as to why a support person accesses services were not explored in any studies. Furthermore, it was elicited through the included studies that the point in which they accessed services in their supporting trajectory, and why, was not explored. This provides an important clinical gap in our knowledge of why some support person’s access support and others do not. Despite this limitation, some studies did however report the length of time individuals had been support persons for, the length of time it had taken them to access support, and an exploration as to why they did not access support services sooner.

Tempelton (2009) identified that family members reported having lived with the alcohol/drug problem for some considerable time, an average of ten years (range 2–20 years), before accessing support. Li et al (2014), recruited 43 family members to complete a structured administered questionnaire, who had reported on average 9 years before accessing any form of help. Sakiyama et al (2014) was the only study which provides qualitative insights into why support persons may not access support. In this study 42% of the 52 participants (n=23/52) reported having sought some form of support immediately after discovering the care receiver's drug use. The other 58% (n=29/52) of participants indicated that they took an average of 2.6 years to seek any help. The reasons shared among the participants included that some perceived that the substance use was transient, and therefore, the support person would not require support. Furthermore, some participants explained they did not know where to access services, whilst others did not feel it was appropriate to access support in their circumstances. Therefore, for these participants they would actively seek help for the care receiver or were asked directly not to access support from the care receiver (person with substance use issues) as they did not want them to be involved. Stigma can constitute significant barriers to support persons accessing support services (McCann and Lubman 2018) and therefore, can have an adverse impact on their effectiveness and ability to maintain their support-giving role (Brown 2011).

Despite no studies investigating exactly why, when or how an individual may access services, these findings provide meaningful insights into how long it can take for an individual to access support. The amount of time varied in each study between 2.6 years to 10 years before support was sought. Furthermore, it highlights why some support persons may not access support. This included, believing that the individual using substances may stop their behaviour, not knowing how or where to access services, potential stigma, embarrassment, and finally the care receiver requesting that the support person does not access support.

2.15 Support being offered

Support for support persons included; informal support, support from general practitioners, support groups, friends, family, and counselling services. However, few studies looked at the type of support offered (informational, emotional, practical, and financial) in any detail. Biegel et al (2007), examined the impact of having a female family member with a substance use issue on the 82 recruited family support persons. Over half, 56% (n=45/82) of the participants indicated that they were unlikely to ask others for help in providing support for the individual that they care for, and almost half 48% (n=39/82) of family support persons had no contact with their relative's treatment provider during the previous six months.

When exploring what support was available to the participants Velleman et al (1993) recruited fifty family members. In their study 88% (n=44/50) of the participants reported that they received some form of support, 74% (n=37/50) reported receiving informal support (family, friends, work colleagues, clergymen) and 60% (n=30/50) acknowledged receiving formal support (professional, agency, such as drugs advice service, community drugs team, GP, Community Psychiatric Nurse, Psychologists and self-help support). Therefore, a high percentage of the participants received both formal and informal support in this particular study. The type of drug used by the individual being cared for led to no difference in support person attitudes towards the individual they supported. However, despite receiving some support 42% (n=18/50) stated that the support they did receive was not helpful, but they did not elaborate as to why this may be.

Findings from this current review provided limited information on what services support persons may access. Furthermore, existing data around the participants own perceptions of available support was very limited. These data confirmed that support persons access support on an informal and formal basis, however despite having services available it is not always found to be of benefit with little explanation as to why.

2.16 Preferences for support

The literature provided insight into what support is available to support persons of individuals with substance misuse issues. Although some support was identified and reported above, it is important to understand what the support was, and if the support persons found it beneficial. Furthermore, it was important to know if the support which is provided would be the preference and if the support person's preferences for support were taken into consideration.

Two studies reported participant's preferences for support (Orr, Barbour & Elliott 2012). Five carers (n=5/20) reported that they had benefited from securing regular support, one being from a generic National Health Service counselling service, two from social work teams and two from third sector organisations. All participants in this study (n=20) highlighted that they wanted more support services for the individual they are supporting, for wider family members and for the support persons themselves. These participants further discussed although they believed that separate services would afford them better opportunities to share their concerns and frustrations, given a choice, they were in support of service providers working with both individuals who use substances and support persons within the same service.

Furthermore, as part of Manthorpe, Moriartry & Cornes (2015) study, most participants were also in support of service providers working with both the individual with substance misuse issues and the support person within the same service. It was further identified in Manthorpe, Moriartry & Cornes (2015) that their participants felt most comfortable discussing their experiences with others who have had similar experiences. Participants suggested that generic carers support groups were not relevant to their circumstances and therefore, unhelpful. Both Manthorpe, Moriartry & Cornes (2015) and Orr, Barbour & Elliott (2012) studies highlighted that the included participants could identify themselves as 'hidden carers', which was a reflection on their experiences and access to support from services.

Two papers explored support persons perceptions of the support available to them (Manthope, Moriatry & Cornes 2015 and Orr, Barbour & Elliot 2012). The participants felt they needed more support which included dealing with the substance use issue for the individual who they supported, but also the physical and mental health aspects which can often be a secondary issue. Participants articulated that they needed additional help with understanding the criminal justice system as individuals affected by substance misuse issues can be entering or leaving prison. Other areas of perceived need for additional support included bereavement and domestic violence in which there appeared to be very little, or no support available for support persons (Orr, Barbour & Elliot 2012).

These findings highlight that support persons accessed both informal and formal support. Although support persons do access support, there were areas which participants felt that they could be improved upon. Firstly, some respondents felt that they wanted more services for the individual that they supported to receive, additional support for the wider family members, which may suggest that they prioritise the needs of others before their own needs. However, this aspect needs exploration in future research. Secondly, support persons also identified that specific support groups for substance misuse support persons would be beneficial rather than generic caring groups. Justifications for this type of support group included acknowledgment that supporting an individual with substance misuse issues would not be relatable to other carer groups due to the increased risk of violence and the chaotic nature of substance misuse. Some participants shared their lack of support when the individual they supported entered the criminal justice system, prison, and a lack of available support during bereavement.

2.17 Effect on psychosocial wellbeing

All respondents in the included studies reported that their support person role had a negative effect on their psychosocial wellbeing to some extent. Velleman et al (1993) highlighted carers described a wide range of short-term negative experiences that included feelings of being: lonely, isolated, tired, drained, unsupported, anxious, depressed, suicidal ideation, guilty, tearful, apprehensive, worried, fearful, tense and confused. A further 94% (n=48) talked about the profound negative changes in their relationship with the individual which they support, describing life experiences of arguments, worsening sexual relationships (with partners), and a breakdown in trust and communication. Furthermore 82% (n=42/143) of relatives talked about long-term negative feelings, or significant changes in physical health which manifested in physical symptoms including shingles, ulcers, raised blood pressure, and psychological effects such depression and panic attacks. The psychosocial effects of the support person role were reflected in Velleman et al (2013) which identified that their supporting role had an impact on their physical, emotional, spiritual and social wellbeing.

Copello et al (2009) conducted a randomised control trial which utilised the brief intervention model. The brief intervention model required implementing an intervention that takes between forty-five minutes and an hour to deliver. Brief interventions are usually conducted in a one-on-one situation and can be performed anywhere on the intervention continuum. This study compared two brief interventions for use by primary health care professionals with family members (FMs) affected by substance misuse issues of a close relative. The design involved a prospective cluster randomised comparative trial of two levels of intensity of intervention. The more intensive intervention was a revised version of the one used and reported in the Velleman et al's (2008) feasibility study, based on the stress-strain- coping- support model of addiction and family. The full intervention included up to five face-to face sessions with the family member. The professional used a range of strategies to help family members identify sources of stress, provide relevant information, about substances, explore coping behaviours and consider enhancing available social support. Each professional delivering the intervention used a manual which guided how to deliver each of the five steps. The brief intervention (BI) that served as a comparison consisted of one face- to-face session with a family member, during which the primary health care professionals introduced the self-help manual. The difference between the two interventions, therefore, was the intensity of face-to -face contact with primary health care professionals. The primary outcome measure included two validated questionnaire measures, entitled The Symptom Rating Test and the Coping Questionnaire.

The symptom rating test measures physical and psychological ill health in the general population. The coping questionnaire measured coping actions/strategies over the previous three-month period. The intervention aimed to reduce scores on both the Symptom Rating Test and the Coping Questionnaire. At 12 months follow up, 56% (n=50/89) of participants thought things were much or slightly better, 24% (n=21/89) saw no difference, and 20% (n=18/89) felt that things were worse in terms of family dynamics.

Ritcher, Chatterji & Pierce's (2000) study aimed to qualitatively examine how Al-anon (Alcoholics Anonymous) members, described their experiences living with an individual with substance misuse issues. All eleven respondents reported their supporting role had led to increasing rates of stress, anxiety and embarrassment, but felt when they had support that this helped to decrease their stress levels. Furthermore, all respondents felt that substance misuse had a significant impact on their wellbeing in a negative way, however did not go into any great detail as to what the negative impacts were. This was also reflected in Slaunwhite et al's (2017) highlighting that participants supporting individuals with substance misuse issues experienced issues with stress, grief, depression, anxiety and changes in their mood. Templeton's (2009) study summarised 26 participants' baseline symptoms prior to a brief intervention being implemented. Out of the 26 participants 76% (n=20/26) experienced some form of psychological symptom as part of their caregiving role, however did not specify exactly what these psychological impacts were.

The most significant forms of stress for support persons were highlighted as, managing their own emotions, finding services for the care receiver and the impact of the care receivers' lifestyle on the support persons overall mental health (Sakiyama et al 2014 and Biegel et al 2007). Slaunwhite et al (2017) identified that support persons of persons with mental health or substance misuse problems were more likely to report the use of specific coping mechanisms to deal with their carer responsibilities such as professional counselling, reading, watching television or listening to music and prescription drug use.

It was apparent that negative consequences exist as part of their caregiving role. Increased stress was reported as being one of the most common consequences. Support persons of individuals with substance misuse issues were significantly more likely to report that they felt tired, worried, anxious, overwhelmed and lonely because of their caregiving responsibilities. Furthermore, these findings suggest support persons manage and cope with their responsibilities and stress through accessing formal support such as GP's, support groups, counselling and prescribed medication to adapting individual techniques such as reading and listening to music.

2.18 Discussion

To begin the discussion on literature review findings, first a reminder of the research questions are provided below:

1. What service support exists for support persons supporting individuals with substance misuse issues?

2. What is the impact on psychosocial wellbeing of support persons?

3. What preferences for support do carers have, and are these preferences being met?

The literature review analysed the findings of 13 papers and identified three overarching themes, Carer profile – who support persons are, Support for support persons and Effect on psychosocial wellbeing. Within this literature review support persons were predominantly female, whom were either parents or partners of the individual they supported with a minimum of 2 years within this role (Slaunwhite et al 2017, Sakiyama et al 2014, Biegel et al 2007 and Velleman et al 2008). Overall the findings of this review suggest that the support person role impacts on their emotional wellbeing in a negative way (Slaunwhite et al 2017, Li et al 2014, Sakiyama et al 2014, Copello et al 2009, Tempelton 2009, MacMaster 2008, Velleman et al 2008, Biegel et al 2007, Ritcher, Chatterji & Pierce 2000, Velleman et al 1993). The findings also suggest that the role of a support person for an individual with substance misuse issues has an impact on their physical wellbeing including short- and long-term physical health conditions. Participants in the studies reported that their supporting role had led them to experience depression, anxiety, stress, isolation, loneliness and worry (Copello et al 2009, MacMaster 2008). The nature of substance misuse can be difficult to manage, as often there are concerns in regard to lack of trust which can have a detrimental impact on the care-giver and care receiver relationship (Frye et al 2008). Often the unpredictability of substance use means that support persons can become anxious and find it difficult to plan for the future (Shah, Wadoo and Lattoo. 2010, Maskill et al 2006). When providing insight into what support persons preferences for support were, only one study highlighted this in any detail (Orr, Barbour & Elliot 2012). The respondents reported that they felt it was beneficial to have ongoing constant support, however did not specify as to what this support entailed. Another key focus from the participants in this study, was their preference was for more services for the individual who they supported. Rusch, Angermeyer & Corrigan (2005) suggests often caregivers can provide invaluable support and often will prioritise the needs of others before their own, which was highlighted within this literature review.

Support for support persons included; informal support, support from general practitioners, support groups, friends, family, and counselling services (Biegel et al 2007 and Velleman 1993). However, despite accessing services, a large percentage in both studies, (over 40%), stated that they were dissatisfied with the support being provided and had no involvement in the care and treatment of the person they supported in the last 6 months. The National Health Service (2010) introduced new guidance 'The triangle of care'. The triangle of care was developed by carers, staff and patients within mental health services to help improve carer engagement in inpatient and community home settings. More collaboration between patient, healthcare services and family members needs to be developed going forward for future practice, despite best practice guidance being available (NICE 2017, Carers Scotland Act 2016).

2.19 Conclusion and implications for future research

These findings suggest that support persons of individuals with substance use issues access support on an informal basis such as friends, family or colleagues and on a formal basis, including their GP, support groups and counselling services. This literature review has identified that whilst there are pockets of support available, this support is not always perceived to be beneficial to the support persons. Furthermore, some participants reported that their support person role differs from other carer groups. Suggesting targeted support for support persons of people with substance use issues is most beneficial. Important considerations were identified in that participants explained they felt they received less practical support and felt that there was an increase in judgmental attitudes or blame when describing a substance use caring role.

The point in which a support person accessed support or why was not explored in any detail in any study providing important directions for future research. However, what the literature has highlighted is reasons as to why a support person may not access services. The reasons included, not knowing where to access services or what services were available, stigma and embarrassment associated with substance use and believing that the substance use was transient and therefore services would not be required. Finally, another reason why a support person may not access services is due to the care receiver directly requesting that they do not access support, however the reasons for this remain unclear.

2.20 Summary

This literature reviews findings have raised the importance and the need for more qualitative research. Further research will help to determine the needs of adult support persons supporting individuals with substance use issues, to gain a better understanding of their experiences as a support person, at what point and why do they access support and identify their preferences for support to implement in service delivery and future practice. Chapter three will discuss the adopted methods and methodology for this study.

CHAPTER THREE: METHODOLOGY AND METHODS

3.1 Research question

This chapter will explore the methodology and methods adopted for this study. This research study aims to answer the following research question:

What are the experiences of support for individuals supporting people with substance use issues and what are their preferences for support?

3.2 Research aim

This is a qualitative study that aims to explore the experiences of support to individuals supporting individuals with substance use issues in the North East of Scotland.

3.3 Research objectives

To address the overall aim of the study the following objectives will be pursued:

1) To explore the participant's experiences of being a support person for an individual with substance use disorders.

2) Explore if being a support person has had an impact on their psychosocial wellbeing

3) To explore what support, support persons utilise (if any)

4) To identify what participants preferences for support are

3.4 Personal position

Boeije (2014) discusses the importance of making it explicit any personal values, assumptions and biases at the outset of any study being conducted. This suggests that the researcher's contribution to the study can be useful and positive rather than detrimental, and they are relevant in interpretative research. Weaver & Olson (2006) describe that human beings cannot be separated from their cultures. Therefore, in acknowledgement of this, there is a need to declare something of my personal beliefs and reasons for pursuing this topic of study.

I chose the subject of this study firstly because of personal experience and passion for working with individuals with substance use issues. I have worked with individuals with substance use issues in various settings including, supported accommodation, prison, mental health inpatient and community settings and specialist drug and alcohol services. As my time, knowledge and understanding of substance misuse grew, so did my awareness of the consequences it had in the broader population, including the consequences for partners, parents, children and friends who at times I had very little involvement with. Additionally, I felt that often the needs individuals supporting people with substance misuse issues are often viewed as secondary to the individual using substances. This started my enquiry into what national guidance, policies and information was available on this particular population group and sparked my interest into investigating this further. Continual and monthly supervisions with my supervisory team allowed the opportunity to discuss the emerging data analysis findings and keep the focus and alignment of that of the research position and not of the mental health and substance use nurse.

3.5 Research paradigms

Research paradigms relate to the beliefs and values that a particular research group shares about the types of phenomena which can or cannot be researched and the relevant methodologies selected (Parahoo 2014). Therefore, it is essential that the researcher has an understanding of the philosophy of the chosen research paradigm for their study. According to Walliman (2017) the purpose of research lies in its intent to create new knowledge. This purpose is often described as a basic set of beliefs which help to guide the researcher to embrace either a quantitative, qualitative or mixed methods approach in their research (Creswell & Creswell 2007).

3.6 Methodology: Qualitative descriptive

This study adapted a qualitative research design. There is a growing evidence base to suggest that the value of qualitative research is significant in identifying the lived experiences of a particular group and a specific phenomenon (Latimer 2011). The basis of qualitative research lies in the interpretive approach to social reality and the description of the lived experience of human beings (Holloway & Wheeler 2015).

As a novice researcher with limited knowledge and experience of research within nursing, exploring research paradigms appeared to be the most appropriate place to start to understand the world of research. The research approach selected a 'best fit' model to enable the research question to be answered (Walliman 2017). The findings from the integrative literature review reported in Chapter two identified a lack of qualitative papers. Consequently, little is known about the lived experiences of individuals supporting people with substance use issues. These findings informed the development of the research question/aims/objectives and a qualitative approach.

With a myriad of qualitative approaches to research, it can be difficult to decide exactly what research paradigm a research question or topic fits (Grix 2004). Qualitative descriptive research studies seek to discover and understand a phenomenon, a process, an experience or a perspective of the people involved (Caelli, Ray & Mill 2003). As a methodology it is becoming increasingly used within nursing and midwifery. Polit and Beck (2014) identified that half of qualitative studies in the previous three years adopted a qualitative descriptive methodology. Utilising a qualitative descriptive approach is helpful when information is directly required from those experiencing the phenomenon being researched and when time and resources are limited (Neergaard et al 2009). Due to the completion date within a two-year period, it was felt that qualitative descriptive would be the best methodology to adopt to this chosen population group to gather data for interpretation.

The philosophical underpinnings of qualitative descriptive research align with subjective enquiry, with individual having their own perspective and each perspective counts (Doody and Bailey 2016). The ontological position of naturalistic research is relativism, which holds the belief that how we perceive reality is subjective and varies from person to person (Parahoo 2014), which is relevant in the reporting of findings of qualitative descriptive research.

Qualitative descriptive studies lie within the naturalistic approach, which creates an understanding of a phenomenon through participant's meanings. Within qualitative description the outcome is to describe the phenomenon literally as a starting point (Sandelowski 2010). Qualitative description design then moves beyond the literal description of the data and attempts to interpret the findings without moving too far from the literal description (Sullivan-Bolyai, Bova and Harper 2005). Unlike phenomenology which looks to 'describe the experiences' of a particular phenomenon, qualitative descriptive studies seek instead to provide a rich description of the experience described in an easily understood language (Sullivan- Bolyai , Bova and Harper 2005).

By adopting a qualitative descriptive approach offers an opportunity to gather descriptions about a particular phenomenon about which very little is known (Caelli, Ray and Mill 2003).

The ultimate goal of qualitative descriptive studies is to provide an account of 'experiences, and events that most researchers and participants would agree with' (Sullivan- Bolyai, Bova and Harper 2005 p121). A qualitative descriptive approach does not require the researchers to move as far from the data compared to other qualitative approaches, however does of course result in some interpretation (Lambert and Lambert 2012). Another strength of qualitative descriptive studies can often provide relevance to practitioners and policy makers (Sandelowski 2000).

3.7 Recruitment

As discussed in chapter one I approached five third sector organisations and two organisations agreed to help recruit participants. The three organisations who declined reported that they did not have any individuals who accessed their service who met the recruitment criteria. In February 2018 I attended two third party organisation family support groups on two occasions to discuss my study in detail with staff and the family members who attended the group. At the first family support session I attended there were eighteen family members at the support group. Out of the eighteen family members, four reported that they would like to take part in the study. At this point the potential participants were provided with the participant information sheet (Appendix eight) and opt in/opt out forms (Appendix nine) to provide contact details and their availability. Participants who agreed to take part were provided with a cover letter (Appendix ten). I further allowed time should any potential participants have any questions; however, no participants did at this stage. For the remaining fourteen participants, they were asked if they felt comfortable to sign the opt-out form and state their reasons why they did not want to participate in the study. Ten Participants signed the opt-out forms and all ten stated that whilst they felt that the study would be important, that at this time it would be too distressing for them to discuss their experiences. Furthermore, all ten family members stated that the individual that they were supporting experienced a relapse in their substance use, and therefore would find it more difficult, and may not be representative of their experience overall.

At the second family support group fourteen members were in attendance. Nine of the participants reported that this was their first time that they had attended the support group and therefore did not feel ready to discuss their experiences in depth as part of the study. A further five participants reported that they had a severe and enduring mental health condition and would find the study too difficult to discuss their experiences. After the second recruitment attempt, I left my contact details with staff members and requested if they knew of anyone else who may not attend the group however that might fit the criteria if they could provide my contact details.

In late March 2018 and early April 2018, I was contacted by four potential participants who had heard about the study through their friends who attended one of the family support groups. I provided information on the study and met up individually to discuss the study in detail. I provided information sheets and offered the opportunity for any questions to be answered. They all agreed they would like to contribute to the study and signed the opt-in form. The recruitment process successfully managed to recruit eight participants for this study. It is important to note that both organisations and participants declined to take part in this study which arguably demonstrates that the informed consent process was robust, this is particularly important where potential participants may be considered to be vulnerable.

3.8 Ethics

Robert Gordon University School of Nursing and Midwifery approved this research project on 2nd February 2018 (Appendix eleven). Furthermore, Ethical Approval was granted from Alcohol and Drugs Action on 12th May 2018. Gaining informed consent from research participants is central to the research process (Boeije 2014). It was, therefore, necessary that I understood the principles associated with informed consent and the process of obtaining informed consent before I embarked on or became involved in any research activity. I completed the NHS Research and Development Informed Consent course at Aberdeen University and completed Robert Gordon University Research Methods module to help develop my knowledge and understanding of ethical principles further.

3.9 Methods: Semi- structured interviews

The choice of a semi-structured interview was reached after exploring the literature relating to substance misuse and support persons. It was judged that a qualitative approach using semi-structured interviews would provide the best approach to use responses of the participant to guide data collection (Miles, Huberman & Saldana 2014). One to one semi-structured interviews constituted the primary data for this study. Interviews enabled the individuals to tell their stories, perceptions regarding their experiences of support and if their preferences for support were taken into consideration, thus, allowing the multiple realities to be elicited.

To help aid with what questions should be asked during the semi-structured interviews, I attended the Drugs Research Network Scotland (2017) conference which included researchers, policymakers, and members of the Scottish Government, individuals with lived experience, and family and friends supporting individuals with substance use issues. I attended the family theme workshop and listened to talks on individual experiences of not only being a support person but also their experiences of support services. This conference allowed me the opportunity to develop ideas, which further enhanced the development of the aim and objectives from the identified gap in the literature review and reflect on possible questions for my semi-structured interviews.

Involving individuals with lived experiences in the process of developing research questions in regard to a particular population group, helps the research project to be guided by the individual/s as the ‘expert’ for a specific phenomenon and improve the study to have more value and reliability (Savin-Baden, Howell & Major 2013). I discussed with five support persons who attended the conference my initial idea for some questions which I thought about using within my interviews, to gauge if they felt the questions were appropriate or not. I discussed two of my working questions and the support persons agreed that they felt the questions were open, appropriate and they would have felt comfortable with how they were asked.

Interviews were all arranged at dates, times and places which suited the participants best. It was important that the setting and environment was right and convenient for the participant and where they felt most comfortable conducting the interviews. I offered the option for the interviews to be conducted in a room at one of the third sector organisations, Robert Gordon University or in their own homes. I offered refreshments and checked at the start of each session if the participant was comfortable in the setting and environment. One participant was interviewed in Robert Gordon University, four in their own homes and three within third sector organisation rooms. For the participants interviewed within their own homes, I made sure to adhere to the NHS lone working policy (NHS Grampian 2016) at all times. Participants were made aware that participation was entirely voluntary and that they could withdraw at any point, without having to give any reasons and with no consequences to their on-going support.

Once I made sure that the participants were comfortable, I then discussed the study in detail and discussed the interview process. The participants were given adequate time to read over the consent form (Appendix 12) and were both signed and dated by the participant and me. It was highlighted that there was the potential that some questions might evoke feelings of sensitivity or potentially distressing feelings when discussing experiences of supporting individuals with substance misuse issues. It was considered with all participants that all responses would be treated entirely confidentially, and if participants felt unable to answer any questions, then they may terminate the session at any time or ask to move onto the next question. For this reason, interviews were only conducted Monday to Thursday, so access to additional support was available, which may not be available at weekends. All participants were able to contact the lead researcher and supervisory team if they had any queries regarding the research project, to make sure they were adequately informed but none did so.

After each interview, I would de-brief with each participant on how they found the process and ask if there were any other questions or final points they would like to share or if there was anything they would like to add. All participants stated that they could not think of anything at that time. After each interview, I would send and discuss each transcription with my supervisory team and present the findings and delivery of the interviews. After the first interview it was noted that all the experiences shared appeared to be negative. After discussion with the supervisory team, it was agreed that perhaps participants thought I only wanted to hear about negative experiences so a question should be added that would identify if there were any positive experiences. This will be discussed in more detail in Chapter four.

In the semi-structured interview schedule (Appendix 13), specific questions were identified, and this was supplemented with prompts when necessary. In keeping with the semi-structured approach detailed by Parahoo (2014) the questions were predetermined as were the prompts. In some instances, interviewees, while answering early questions, provided answers to questions posed later in the interview and where this happened the subject matter was not addressed a second time. All questions were covered with each respondent. Denzin and Lincoln (2006) describe that the purpose of qualitative research is to study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people give to them.

3.10 Semi structured interview questions

The semi structured interview questions were developed in April 2018 and agreed with the supervisory team. The aim was to ensure that the study aims and objectives could be met through the use of these questions whilst allowing enough flexibility for participants to tell me what they thought was important. The semi structured questions are displayed below:

Question 1	Can you tell me a little bit about the person you support and your experience of supporting them?
Question 2	Was there a particular event as a support person that you remember distinctively?
Question 3	What was the biggest challenge you faced at that time?
Question 4	Have there been any positives with being a support person or experiences of support?
Question 5	Are there any services that have helped you?
Question 6	In what way have they helped you?
Question 7	Do you have any other support that you find helpful?
Question 8	What do you think would be the best service to provide support and what would be the best method?
Question 9	Overall, how do you feel your needs as a support person are met?
Question 10	Is there anything else you would like to add, or any final comments?

3.11 Population

The population in this study was adult support persons of individuals with substance use issues living in one area in the North East of Scotland.

3.12 Inclusion and exclusion criteria

Participants considered for inclusion were/or have been a support person for a person/s who has a confirmed diagnosis of substance misuse issues. They were also:

- Aged 18 years or over.

- Able to read, write and speak English to a sufficient level to participate in the data collection.

- Able to understand and provide written informed consent. There was no limitations set on the substance misuse type, symptoms or severity of the condition, or length of time receiving support from the participant.

Exclusion criteria:

- Diagnosis of a severe and enduring Mental Health condition

- Aged under 18 years old

3.13 Sampling

Qualitative descriptive studies generally adapt a purposive method of sampling participants as they have knowledge and experience in the phenomenon being researched (Polit and Beck 2014). Purposive sampling was the approach chosen for this study. This is a specific type of sampling method that relies on data collection from population members who are conveniently available to participate in a study (Stanley 2015). As illuminated in the literature review (chapter 2) recruitment for individuals with substance use issues historically has been difficult and I have outlined my approach above in section 3.7. Within substance misuse research it has been well documented that there are many barriers regarding recruitment (Bolland 2008). Individuals who have substance misuse issues are some of the most stigmatised individuals in society (Geurden et al 2013). Some of the reasons for this have been linked to views that substance misuse is seen as a 'choice' which leads to stigmatising views (Bolland 2008). Therefore, associated stigma can make it challenging to support persons to be open and honest about their support role (Van Boekel et al 2013).

Another explanation as to why support persons of individuals with substance misuse may not access support is that some individuals as mentioned in Chapter two literature review findings, do not consider themselves as a carer or support person. The supporting/caring role generally manifests in aiding with physical elements of care for an individual, which often is not the case for individuals with substance use issues. The literature review and wider reading undertaken provided informed insights into deciding on the recruitment and sampling process which was best for this study.

Sample size should depend on the aim of the study and analysis strategy (Malterud, Siersman & Guassora 2015; Guest, Bunce & Johnson 2006). This study originally aimed to recruit ten participants to conduct 1:1 semi-structured interviews. I have detailed above some of the challenges in sampling support persons and managed to successfully recruit eight. Latimer (2011) highlights that there is no specific number which should be implemented in qualitative practice, but rather the participants should be an amount that can answer the question, aims and objectives of the research. Due to the time scale of two years for this project to be completed and recruitment localised to one area, it is identified that eight participants would be a sufficient number to identify themes for analysis.

3.14 Data storage

Interviews were audio recorded on a dictaphone and transcribed by me. After transcription, the interviews were deleted from the dictaphone and the interview data was only stored electronically. Any quotations used in this final report and subsequent publications is anonymised data. Data were stored on a password-protected university computer and transferred to a secure university network. The password-protected university computer is stored securely via swipe card access at Robert Gordon University. Any paper copies of notes from the interviews are stored in a swipe accessed room, in a locked filing cabinet in Robert Gordon University Health and Social Care Building.

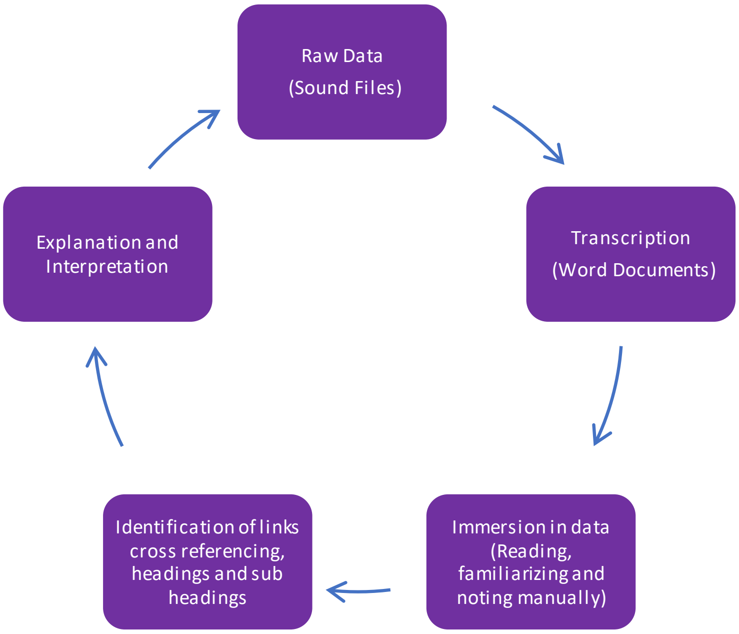
Audio recordings will be destroyed securely at the end of this study, which was in line with good clinical practice (GCP) guidelines, The Legislation Data Protection Act (2018) and the NHS Grampian Code of Practice on Confidentiality (2016). Best practice was monitored by my supervisory team at Robert Gordon University. All information collected during the study were kept strictly confidential. Identifiable data will be stored for 6-12 months after the study has ended, and unidentifiable data will be saved for five years.

3.15 Thematic analysis

When conducting data analysis, the researcher becomes immersed in the data making judgments about coding, theming, decontextualizing and recontextualising data (Green & Thorgood 2009). This study utilised thematic analysis to conduct the findings. There is no specific research design associated with thematic analysis. It can be employed for case studies, phenomenology and generic qualitative studies including qualitative descriptive designs. Castleberry & Nolen (2018) state that thematic data analysis is ideal for both novice and expert qualitative researchers.

Thematic analysis is a method for identifying, analysing, organising, describing, and reporting themes found within a data set (Braun & Clarke, 2012). Miles, Huberman & Saldana (2014) state that thematic analysis is a method for understanding the perspectives of research participants. This allows for similarities and differences to be drawn from the data and generating unanticipated insights. The process of how I conducted thematic analysis is shown in Figure Two.

3.16 Figure Two: Process of thematic analysis



However, there are some disadvantages of thematic analysis when considered against other qualitative research methods. While thematic analysis is flexible, this flexibility can lead to inconsistency and a lack of coherence when developing themes derived from the research data (Vaismoradi, Turnunen & Bondas 2013). Consistency and cohesion can be promoted by applying and making specific an epistemological position that can coherently underpin the studies empirical claims (Finlay 2006).

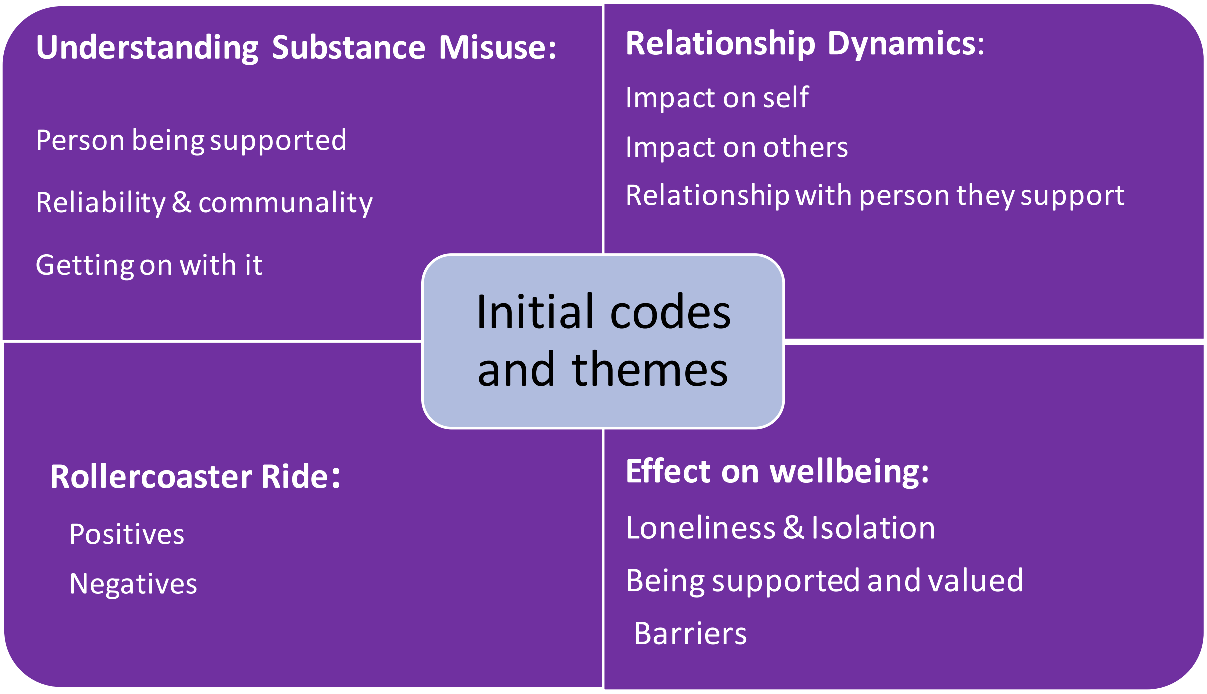
3.17 Thematic analysis process

After each semi-structured interview was conducted, I then transcribed the interview within twenty-four hours of the interview taken place. The format of transcriptions was standardised across interviews, for example, all questions asked of interviewees were recorded in bold type and all responses in normal type (Grix 2004). This enabled consideration of question and response as a whole and made relocating sections of text easier later in the analysis process. Listening to the recorded interviews and transcribing verbatim allowed the identification of vocal intonations, pauses and non-verbal sounds that conveyed the interviewee's emotions while talking about a specific topic. These were noted on the transcript to remain visible when rechecking to verify themes. A poignant example occurred when an interviewee became tearful as she reflected on her experiences of being a support person. This powerfully illustrated the strong feelings she had when discussing the impact this had on her own wellbeing. By conducting the transcriptions on my own, it allowed me to have the interview fresh in my mind and as I was listening, I would add comments to my reflective diary. Field notes were also gathered at the time of the interviews and recorded in note form to reflect the situations under which interviews took place. In addition, the notes were used as reminders of characteristics of the interviewee and the context as regards location, surroundings and time. These strategies helped me ensure my approach to analysis was open to what actually was said and experienced.

Data analysis started from the first interview where I would reread the transcript and fully immerse myself in these data and the meaning of what was being said. Comments were made at the side of the pages detailing my interpretation of the narrative. Interview transcripts were initially read and reread in order to become familiar with the texts. A numbering system was applied to the texts to pinpoint relevant extracts. Highlighter pens were then used to start making comments and connections on what was being said. The interviews were coded in groups initially. Issues such as the effect on the relationship with person they support, the effect on self; loneliness and understanding emerged. These initial codes were linked to relevant passages in transcripts that are identified by coloured bars and were easily retrievable as the analysis process progressed.

The second phase of data analysis began once I had familiarised myself with these data (Braun & Clarke, 2006). This phase involved the initial production of codes from the data, a theorising activity that required me to keep revisiting and questioning these data further. An example of some of the initial codes are shown in Figure Three. Qualitative coding is a process of reflection and a way of interacting with and thinking about data (Sandelowski 2010). Coding allowed me to simplify and focus on the specific characteristics of the data. It is important to note that although computer programs may be helpful to organise and examine large amounts of data, none are capable of the intellectual and conceptualising processes required to transform data into themes and subthemes, nor can they make any judgment (Pope & Mays 2006). Thus, I felt due to the early stage of my research career that it would be more beneficial to conduct thematic analysis manually to understand the complexity of analysis and coding.

3.18 Figure Three: Initial codes



The third phase began when all the data had been coded and collated. This phase involved sorting and organising all the potentially relevant data and transferring these into themes (Braun & Clarke, 2006). A theme can be initially generated inductively from the raw data but also can be made deductively from theory and prior research (Green & Thorogood 2009). At this stage, I used tables, produced in a word document, mind maps, and colour coding with different coloured highlighter pens to help aid with identifying potential themes shown in Appendix fourteen**.** Braun & Clarke (2006) and (Pope & Mays 2006) suggest that by adopting less structured and more creative approaches such as maps and other diagrams, this may be a useful way to explore and display relationships between themes beyond the sequential template (Vaismoradi, Turunen & Bondas 2013).

The fourth phase began once a preliminary set of themes had been devised, and they now required refinement (Braun & Clarke, 2006). Once preliminary themes were identified the lead researcher and two supervisors discussed the evolving themes. Supervisors provided regular feedback, challenge and discussion around developing the emerging themes further. Refinement occurred on many occasions and with guidance from the supervisory team to identify the 'golden thread' running throughout this thesis. Part of telling the participant's story was ordering the themes in a way that best reflected the data. As a team, the themes were organised and reorganised until consensus was reached, and all team members were satisfied that data were represented and displayed in a meaningful and useful manner in the thematic framework. The final phase began once I had sufficiently established the themes and was ready to start the final analysis and write-up of the study (Braun & Clarke, 2006).

3.19 Conformability

Conformability is concerned with establishing that my interpretations and findings are derived from the data, requiring me to demonstrate how conclusions and interpretations have been reached (Burnard 2011). These interpretations were further enhanced by the use of a reflective journal. Furthermore, the findings represent the data across the data set and not biased by my own views which is evidenced by inclusiveness of direct quotes from all the participants, and ongoing monthly supervisions with my supervisors.

3.20 Credibility

Lincoln and Guba (1985) claimed that the credibility addresses the best fit between participant's views and the researcher's representation of them (Holloway 2005). Credibility involves establishing that the results of qualitative research are credible or believable from the perspective of the research participant (Holloway 2005). Therefore, to ensure credibility within this study the transcripts of the taped interviews were offered to the respective respondents for comments on accuracy, and this also provided an opportunity for the participant to check the validity of the themes drawn from the data by the researcher, however all participants reported that they did not feel that this was necessary. After each interview I discussed my field notes with participants and discussed what I had elicited from their interview. All respondents reported that they were happy with the filed notes and my interpretation of what had been said, with one participant indicating that they were glad I included change in body language and facial expressions as this 'brought what they were saying to life'. Thus, the themes drawn were checked to establish whether or not they matched the intended message provided in the individual's response to the questions posed.

3.21 Trustworthiness

Throughout the data analysis a reflexive journal was kept (See extract in Appendix fifteen). The practice of reflexivity is an essential component to incorporate to demonstrate trustworthiness (Finlay 2006, Kingdon 2005). Reflexivity requires critical self-reflection of the ways in which the researcher's assumptions and positions may affect the research process (McCabe and Holmes 2009). Measures proposed by Lincoln and Guba (1985) were used to ensure the validity and accuracy of the data. Data credibility was done using continuous data comparison. To be accepted as trustworthy, qualitative researchers must demonstrate that data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible.

Castleberry & Nolen (2018) suggests that if readers are not clear about how researchers analysed their data or what assumptions informed their analysis, evaluating the trustworthiness of the research process is difficult. Qualitative researchers can demonstrate how data analysis has been conducted through recording, systematising, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible (Streubert & Carpenter 2011). Continual engagement with the supervisory team during the data collection and analysis process alongside feeding back to participants ensured the trustworthiness of these findings.

3.22 Transferability

The employment context, age, gender and length of time participants had been a support person were recorded. In qualitative research, according to Ryan-Nicholls & Will (2009) it is concerned with the degree of transferability to other contexts. Purposive sampling was adopted which allow this population group to be studied in alternative areas.

3.23 Summary

In summary, a qualitative approach using semi-structured interviews was utilised to develop an in-depth understanding of the participant’s experiences of being a support person of an individual with substance misuse issues. Chapter four goes on to describe the findings from the semi- structured interviews.

CHAPTER FOUR: FINDINGS

4.0 Introduction

This chapter presents the findings from the semi-structured interviews conducted from June 2018-July 2018. The interviews explored support persons experiences of supporting individuals with substance use issues. The findings illuminated participant's perceptions of what was beneficial support, and what their preferences for support were. Analysis of data aimed to address, the following objectives of the overall research:

1. To explore the participant's experiences of being a support person for an individual with substance use disorders.
2. Explore if being a support person has had an impact on their psychosocial wellbeing
3. To explore what support, support persons utilise (if any)
4. To identify what participants preferences for support are

4.1 Participant demographics

As discussed in chapter three, eight participants were successfully recruited to take part in this research study. A table of the participant demographics is displayed below. In table three the sex, age, occupation and length of time participants had been a support person was documented. Furthermore, the sex, age and substance used by the individual they supported was recorded.

4.2 Table Three: Participant demographics

Participant Number	Sex of participant	Relationship of person they support	Age of support person	Age of person they support	Occupation	Substance used	Number of years supported the person with substance use disorder	Number of years substance has been problematic (Impact on psychosocial wellbeing)
Participant 1	Female	Father	45	59	Healthcare Support Worker	Alcohol	3	3
Participant 2	Female	Husband	45	42	Healthcare Support Worker	Heroin, crack cocaine	14	12
Participant 3	Female	Daughter	53	37	Community Mental Health Nurse	Cannabis, Heroin	20	20
Participant 4	Female	Son	51	23	Radiographer	Cannabis, Cocaine	5	5
Participant 5	Female	Son	58	25	Pharmacist	Heroin	4	4
Participant 6	Female	Husband	65	69	Retired	Alcohol	2	2
Participant 7	Male	Son	68	30	Retired	Heroin	15	10
Participant 8	Male	Brother	34	39	Offshore engineer	Heroin, Cocaine	10	5

4.3 Themes and categories

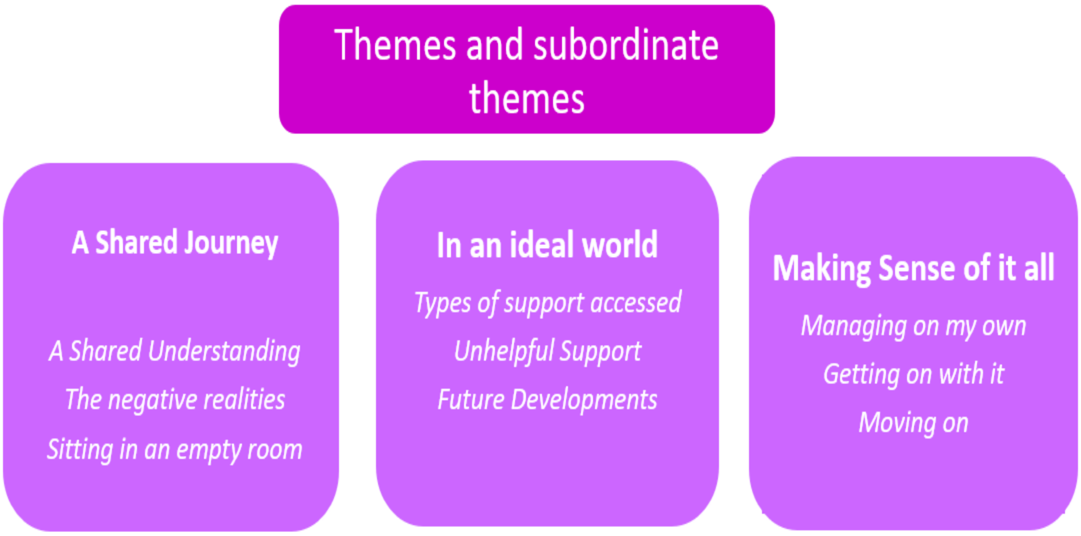
The themes that were developed through the process of thematic data analysis identified three organising themes entitled: ‘A shared journey’, ‘Making sense of it all’ and ‘In an ideal world’ as shown in figure four. The first organising theme reflected a shared journey in many aspects of the support person role, and within this, there were three superordinate themes. The three subordinate themes are entitled ‘A shared understanding’ which provides insight into what support the participants found valuable. Furthermore, ‘The negative realities’ and ‘Sitting in an empty room’ highlight the negative consequences of the role including loneliness and isolation.

The second theme ‘Making sense of it all’, provides insight into how support persons understand, adapt and cope with their role. The subordinate themes of ‘Managing on my own’, ‘Getting on with it’ and ‘Moving on’ describe the participant's reflections on their roles and when or if they accessed support to meet their needs. ‘Moving on’ provides a narrative to suggest that some participants reach a point of acceptance within their role and can prioritise their own needs first again, rather than the individual who they support.

The third theme is ‘In an ideal world’ which illuminates what support persons would find the most beneficial support that they could access. The three subordinate themes are ‘Types of support accessed’ ‘Unhelpful support’ and ‘Future developments’. When describing types of support that the participants have or would find helpful, this varied between the interviewees. The subordinate theme ‘Unhelpful support’ describes what participants have accessed in the past which they have found unhelpful. And finally, the third subordinate theme ‘Future developments’ suggests participant’s preferences for support for the future.

Each of these themes will be discussed separately although there are links between and across the themes and categories. The process of developing the themes and categories was described in chapter three. The choice of which quotes to use was challenging given the richness of the data set. The decisions were made based on several important considerations, namely: quotes that were succinct and representative of several of the participants’ discussions, quotes that were different to others’ and demonstrated the differences in experiences; and finally, those that simply encapsulated an experience as a whole (Starks & Trinidad 2008). Mind maps and other notes were used during the iterative process, and the rereading of the transcripts and writing and refining the findings enabled me to develop my understanding of the ‘whole’ data set.

4.4 Figure four- Themes and subordinate themes



4.5 A shared journey

In the context of this thesis, 'A shared journey' was used to describe the participant's experiences of being a support person and the support which they received. Throughout the interview's participants discussed common and similar descriptions and experiences. Therefore, the overarching theme 'A shared journey' was constructed. Within this shared journey of the support person role, each participant also made a significant and unique contribution to the findings of this study. The overarching theme of 'A shared journey' will be discussed alongside the sub-themes which at times overlap. The presentation of findings illuminates where participant's experiences differed.

All participants identified a situation or events which had led them to the support person role. This was described by all participants as a negative experience when the substance use was initially brought to light and the realities of their role became apparent. While many aspects of the role, thoughts and feelings were similar amongst participants, there were some factors which did differ and these will be discussed further in other themes.

4.6 A shared understanding

Participants in this study identified the importance of having individuals to turn to who understood their experiences as part of their support person journey. The supporting role was described in different ways such as, 'feeling like you are not alone', 'knowing what you are going through', and 'just getting it'. While the relationship between those who had this shared understanding varied from being partners, friends and family members, or a combination, all participants discussed what made the support they received valuable. All participants described that they found it beneficial and helpful to have that shared understanding with others who have or had similar experiences as their own, some quotes to emphasise this are highlighted below:

> *"It's really good because it's a place you can say anything you like and people will understand because anything I have said about my son it won't matter because they would have said the same about theirs". [When talking about local drug and alcohol carers support group] [Participant 4]*

> *"Having the friendship of people here [Local drug and alcohol carers support group]…who do….get it, and as much as I have got great friends, it's difficult to get someone to understand. They listen, and they say yeah that must be awful, but they don't really*

understand, but that’s not a failing on them, it’s just..well the people here get exactly what you are going through”. [Participant 5]

Another participant further described the importance of not just having friendships and support available but also that the person understands the events that they are discussing and the support person’s role. While it is important to have support from friends or family members, this quote suggests that the support perhaps may need something more than just being a supporting figure and listening:

“Yeah, I have great friends, it took me a while to tell them, and I told them incrementally, so that was difficult as it was all so horrible and all so much. But the friends that I have, have been great, very supportive. They don’t know what they’re talking about, of course, nobody can do unless they have been through it themselves”. [Participant 5]

A further three participants described what support that they perceived as useful and described it as ‘knowing you’re not alone’ on this shared journey. All participants identified that knowing you’re not alone was valuable as often their caring role can lead to loneliness and isolation. The value in the support is not only a platform to talk, but also a platform whereby there is a shared understanding of the realities of the role and a place of belonging:

“Aye [yes], knowing that you’re not alone, and listening to other people going through the same thing to give advice or even to understand what it is you’re talking about”.

[Participant 8]

Although not all of the interviewees had accessed any formal support services, all could recognise times or situations whereby it would have been beneficial for them to have done so in the past. For the individuals who did access services, it appeared that these feelings of loneliness, isolation and the impact of the supporting role had led them to seek further support to allow them to find hope and feel part of a community where they could be open and honest about their experiences and the emotional impact of their role.

One participant drew on their experience of being a support person of an individual with substance misuse issues and how they felt that their support role experiences would have differed from other groups of support persons. The lead researcher asked the participant if they could explain this further when discussing support services for carers of other illness which the response is highlighted below:

"Well, they wouldn't understand [Generic carer support group]. Like I suppose if someone is there because their son has bad diabetes, it's not going to be the same as me talking about my son who uses heroin, well..it might..but I hardly think they would understand, or be going through the same things. Maybe I am judgemental, but I wouldn't find that helpful, It's important that I can talk to others who might have had some of the same issues as me, or maybe I can offer them suggestions because I have been where they are, that's very important. The things we have to go through I wouldn't wish on my worst enemy, lies, theft, physical abuse, overdoses". [Participant 7]

Moreover, the superordinate theme of 'Shared understanding' was valued as important irrespective of the substance (alcohol or drugs) being used by the individual that they supported. One participant articulated the shared experiences as:

"The first time I went I was the only one with alcohol problems and all the rest were drug problems, but I discovered our feelings are very similar. We all feel helpless, hopeless, angry have all the same emotions, so it is helpful to hear other people's stories, and in all honesty, a lot of them are a lot worse than mine". [Participant 6]

While the participants varied from accessing formal support to only discussing with close family and friends, and supporting individuals with a variety of different substances, there were key points that appeared to be common to participants. The first was valuable elements in the support they received. Having an environment and people where the participants felt safe to talk about their experiences, without judgment, was key to feeling the support was valued. Furthermore, all participants reported what they found beneficial was being able to talk to individuals who may have had the same experiences and an understanding of substance use and their supporting role. All participants described that the supporting role could often leave them feeling lonely and isolated. This would suggest that there is an element of the role that makes the support person feel alone, which the subordinate theme 'Sitting in an empty room' will go on to describe.

4.7 Sitting in an empty room

All participants described at some stage that being a support person had led them to feel alone, lonely, isolated or experience feelings of hopelessness. This subordinate theme 'Sitting in an empty room' describes that while some participants had accessed services, often something that comes hand in hand with the supporting role are feelings of loneliness and isolation, despite accessing support:

“I guess what I am trying to say is that I am on my own, I do not have a support network at home, just trying to find anybody that will understand has been a priority for a while”. [Participant 5]

“It leaves you feeling a bit ... helpless and hopeless I suppose, because if they [an individual with substance use issues being supported] don’t want to address it? As a support person, you can’t do it for them, you’re on your own with it”. [Participant 3]

“Even going to counselling myself, it is just, I feel like, I am trying loads of different doors, it is very lonely at times. And it is just tiring…it’s tiring knowing that you are kind of isolated and you have to make an effort to find the help”. [Participant 4]

The above quotations illuminate that while accessing support helps in bridging the gap of feelings of loneliness and isolation this could be short lived. Family support sessions offered the opportunity to discuss, share, listen and provide help and advice to others in the same or similar situations, out with those support sessions it could still be a lonely and isolating role:

“It’s terrible. It’s like a nightmare that never ends. I kind of kept it secret for a long time, until it became too awful and I could no longer keep it as a secret anymore. Yeah as I say..every parent’s worst nightmare really. It was the worst experience of my life bar none and believe me I have had my share of difficult times”. [Participant 5]

“I was very down and felt very alone. I think how I was feeling made me want to look for support; at one point I was considered separating from my husband”. [Participant 6]

“Feeling almost helpless or ah, futile in your, you know your efforts to try and help them it can feel quite isolative and em a bit like your kinda [kind of] standing on your own with it. Yeah maybe to know you’re not alone you know, you were flying blind a lot of the time”.

[Participant 8]

Often participants described that it was easier or preferable not to let others privy to their circumstances, such as friends or work colleagues. Many described not seeking help until they found it to challenging to manage themselves, or an incident occurred which many disclosed as a “crisis”, which almost forced them into a situation where they had to tell others and seek support not only for the individual that they are supporting but for themselves.

4.8 Negative realities

Being a support person can impact on psychosocial well-being and their relationship with the individual that they are supporting often can be impacted:

> *"That's why I take a back seat because he is my son, I am his dad, and I love him, but sometimes, well a lot of the time it can be hard to like him. I know that sounds bloody awful, it took a long time for me to come to terms with that I struggle to like my own son, but the reality is we love him and always will, but we can't stop him as much as we want to, and that is the most infuriating thing". [Participant 7]*

> *"I get very angry …and I get very hurt because I feel that he is choosing the alcohol over me. And…we did…we have had a very good marriage, and he has, we really were good together, and I feel like he has just taken a hammer to that, because it's almost like, I don't recognise him as my husband anymore. It's just so different as I would never have expected this of him, and I just feel like he has let me down". [Participant 6]*

Two participants stated that there were some positives of being a support person. The participants stated that it had strengthened the relationship with either the person they were supporting or with another individual also supporting the same individual:

> *"I think it, it was quite positive I suppose, it was really stressful at the start when we first started dating. I suppose hmm my first conversation was although I really did love him, I loved my kids more so I had to be 100% sure, and he had to 100% put his trust in me and know that I was there to help him" [Participant 2].*

> *"I know him inside out, more so than I think I ever would of [If care receiver had not taken substances]. Our relationship was very good anyway, but it's now a whole different level because I know every little part of his behaviour, I know when he's lying, and I've also had a bit of an insight into…..I think his mindset and why he does these things [heroin and cocaine use] but yeah I mean it is positive because you know he trusts me….but it's also forced our family to talk about it, and you know turn to things that maybe, you maybe wouldn't want to address if you didn't have to but em I would say that's the main positive, one of the few positives anyway of this whole thing"*
>
> *[Participant 8]*

Despite there being some positives for some individuals, the next quote was representative of six participant's experiences of feelings of no positivity within their support role:

> *"No, no I would not wish this on my worst enemy. My parents in law were always close, so that's not been a positive because I have always loved them and I've always thought they were great. My two other children I am cross with as they have no relationship with him now*

, I park that because they are my children too, but I am cross and disappointed in them for that, and they know it, so that hasn't been a positive. It has all had an impact on my work. I was studying and had to delay my studying. No, I can't think of anything positive".

[Participant 6]

Participants in this study overall reported that being a support person impacted negatively on their psychosocial wellbeing, including family relationships, emotional wellbeing and working life.

4.9 Making sense of it all

Support persons in this study shared many elements of this journey, including an impact on relationships and feelings of loneliness and isolation. The findings revealed some variations in levels of acceptance and understanding of the substance use and its consequences. During the interviews, it appeared that the participants were at different stages of not only accepting their role, but also adapting to it.

4.10 Managing on my own

Three participants discussed why they felt that they did not want to access any formal services for support. The below quotation is representative of those participants and describes that they did not feel that accessing support was a priority, and rather the focus was on the needs of the individual who they are supporting:

"I always thought you know; I'm not the one with the heroin addiction going through it, I am not the one addicted. I suppose the heroin and methadone was different, mentally I'm strong in my head anyway, and a lot of time I would use like a third person I suppose in my own head to justify things, I can be my own counsellor and have a conversation in my own head at times to rationalise things". [Participant 1]

Three participants appeared to be at what seemed the beginning of the support person journey. They described that they did not feel that they required support as they could rationalise or work through things themselves. From the field notes, they further described this as 'Managing on my own'.

4.11 Getting on with it

Participants reported that their role as a support person was difficult and challenging requiring them to adjust, adapt, understand and accept their situation:

> *“I definitely have struggled with this whole thing [When talking about being a support person], drug use is chaotic, and it is difficult to see where you fit into it all, you can’t make them stop using, so you’re just trying to muddle through as best as you can”.*
>
> *[Participant 8]*

‘Getting on with it’, describes that often there was an expectancy to take on this supporting role, with little choice or preparation. Some participants discussed that they had never located support services and that they found that by talking to close friends and family that this provided enough support or them:

> *[When discussing accessing support] Probably in the future but not right at this minute because I dinnae [do not] see it as a priority. It’s my life, and as long as I keep speaking about it, with my sister, and my mum, for me, that’s enough just now and my partner. [Participant 1]*

> *“No really, I suppose just that expectancy to just get on with it, I have just gotten on with it, and because it is different days since the second one come along [discussing second grandchild who had guardianship for] but then you were just kind of left to get on with it because you’re the family member”. [Participant 3]*

These two quotes from the participants illuminate why an individual may or may not access services for support. The first illuminates that by having individuals who they can speak to within their social circle can provide valued support in itself, and therefore excluding the need to get in contact with further or broader support services.

The second quote focuses on the notion of expectancy and lack of choice. This participant told their story of her daughter who had substance use issues. There was expectancy for the participant [the grandmother] to take custody of the children, and further adopt the support person role. Very little choice was executed in taking on this role, which was representative of most participant’s experiences of how they adopted their role:

> *“It’s not always in the best interest of the child, to be kept in the family. I think that social work really need to look at that I think. You might think you’re doing the right thing by keeping the child in the family, but the person who is using is still there in the background you know? As I said I tried to protect them as much as I could, especially when they were little [Grandchildren] and I was just left,as they thought, oh gran will just do it, aye well what*

about my thoughts or needs, did anyone ask about that..no. My needs? My needs ha, well my needs were never met. It was always my daughter and her children's needs that came first especially the children". [Participant 3]

There appeared to be a time when support persons would move from managing on their own, to accessing services and more formal support. Often the participants would describe this change in support seeking as 'getting on with it'. They realised that often, they were the only ones able to care for the individual they are supporting, and there was no other choice but to adapt to the role. Accessing services to help with the role often occurred after an incident or series of events which left the support person in a state of crisis and reaching a breaking point:

"I was very down and felt very alone. I think how I was feeling made me want to look for support at one point I considered separating from my husband because it got to stage where I resented him. And if he kept drinking, I didn't think I could stand by and watch it, and I really thought that I had to get out of the relationship, however…I accessed the support, and it has helped I must say". [Participant 6]

The above quotation was representative of the four other participants who accessed more formal support. It was evident that the participants could easily pinpoint an example, emotion or situation that changed from managing the role on their own to looking for support. This quotation also suggests the conflict in that transition from being a wife to now a support person. Furthermore, it highlights the negative impact substance use can have on relationships.

4.12 Moving on

When discussing the experiences of being a support person and also the support which was accessed, it became evident that three participants differed from the others. There was a sense of acceptance of not only their role but also recognition and understanding that the choices and behaviours of the individual they supported were not their responsibility. However, to get to this stage, it required a process of adjustment and appeared to be a difficult conclusion to reach. While this acceptance had been welcomed, there did however seem to be a conflict in that there was still a huge emotional bond with the individual they support, which can make it difficult to move on from the role entirely:

"I feel more accepting that my son's addiction is not my fault; he had a loving family, a loving home, wanted for nothing. Something happened that made him want to take drugs, and what that is I might never know, but as I said earlier he is a grown man, and I can't keep living my life around him. Do I worry about him, yes, every single day, but it doesn't stop me from

> *going on holiday now or trips away as it used to before. I hope one day he changes and stops his drug use, but I can't hold out for a day that might never come. I can just always be there when he needs me [smiling"]. [Participant 7]*

This quote suggests acceptance of no longer blaming themselves and recognising that the substance use was not the participant's fault. It further suggests that although this role still provides challenges and worry, there has been a shift within the role that has allowed the participant to no longer let the role consume and impact as much on their wellbeing. It ends with a tone of hope. While the participant identifies that they have no control over the individual's level of drug use, there is a warmness in both the words and the physical actions of smiling that reinforce that there was still hope and acceptance. Another participant discussed this notion of hope:

> *"He's still my brother; he's still that person, he's not defined by his use of drugs and I will never let that be the definition of him for myself or for anyone. You always have hope, well for me anyway, that will never go away, it's tested at times yes to the max but yeah you never let that fade, I think once that goes [Hope] then you have nothing left".*
>
> *[Participant 8]*

Hope appeared to be one of the differences between the participants who had reached this stage of acceptance and those that had not. Whilst there remained difficulties and conflict within the role, all participants at this stage discussed that a vital part of the role, and managing the position, is by being able to recognise and install hope into their situations. It may not always be this way and that the individual being supported may be able to recover.

Another participant described their story and stage in line with 'moving on'. It highlights reflection within the support person role over their journey and the value of the support they received. This description further encompasses the notion of acceptance and adaptation within their support person's role:

> *"I think I have kind of moved on now. I have been going for three years now, and I feel that I want to kind of move on now, so I won't be going back…and if I do go back, then it means things aren't good and really bad again, which they may well do I don't know. But I feel that I have moved on and I, I like the people there, some have been going for years, some are new, but I kind of feel like I don't want to immerse myself in that world every second Wednesday". [Participant 5]*

This quote further highlights that there has been a shift within the support persons role, a sense of adapting has taken place from the priority being on the support person and their loved ones needs to the needs and wellbeing of the support person themselves. This participant explains that while they value the support that they have received, they are now focusing on themselves and no longer feel that the support group needs to be a constant, but instead, it is always there should they need to re-access it.

> *“Of course, there are things I would do; differently, hindsight is a wonderful thing, but my other two are fine, they are doing just grand. They showed me that I will always love him, but he is not my responsibility, he’s his own responsibility. My responsibility is me, and I have to make sure that I’m alright. Talking to someone who knew what was what helped encourage and assert myself and made me realise I can’t save him, all I can do is save myself”. [Participant 5]*

The above quote identifies this shift and process of acceptance and moving on as part of the support person role. It is apparent that there is an element of reflection on how and why things may have occurred; however, the participant no longer felt that the substance use was their fault or indeed their responsibility. From the interviews, it was evident that this was a long and at times emotional process for the support person to reach a stage of acceptance and ultimately to allow themselves the permission to focus on themselves and moving on from the role.

The third participant reflected on the support they provided to the individual with substance use issues and how this had changed from being wrong or entering a blame culture of what could have been done differently to acceptance:

> *“I think it’s certainly made my parents think what have they done wrong what could they have done differently, but I think we’ve got to a point now where it’s you know you have to look past that. It's not about what have we done wrong it’s about the choices that he’s made even given all the support and information that he has, you have to take a stand at some point and say no this is you, you’re making the decision, its self-destructive behaviour but you’re aware of it”. [Participant 8].*

The three participants who seemed to have reached this stage of acceptance and allowed themselves to “move on” the relationship to the person being supported were a mother, a father and a brother. Different relationships did not appear to make a difference to the individual being supported and at what point the support person may wish to detach themselves from this role.

4.13 In an ideal world

When describing what support was helpful and what their preferences for support would be, many participants described it in idealistic terms; therefore, the theme ‘In an ideal world’ was reached. The participants who accessed substance misuse support services discussed their experiences in favourable terms, with some describing the quality of the support as being ‘life-saving'. Some participants identified that having facilitators and staff who understood substance misuse and the impact this may have on the support person as important. Furthermore, all interviewees thought that the individual or service providing the support needed to have a non-judgmental approach. Some participants felt that they were able to cope and manage with the support from their friends and family, while others felt they required more formal forms of support. Some accessed one to one support, telephone support and others discussed support person groups.

4.14 Types of support accessed

Having someone to talk to, non-judgmentally in a safe environment where they felt valued and listened to was important. However, what did appear to be different with the participants who obtained formal support compared to those who did not was that the formal support appeared to provide additional information on ways that may help or hearing other people's situations allowed others to deliver what they had done in similar circumstances:

[When discussing local drug and alcohol carer support group] "The understanding here, the support workers here are great, they obviously put a lot of time and understanding and effort into knowing the stuff that they work with. Understanding carers as well as the users, yeah just very understanding, very helpful with anything you ask". [Participant 5]

"They provide just a platform where you can talk about well probably the crap bits about our lives and other people understand it and won't judge you for it, and I think that's very important". [Participant 6]

"I don't really speak much I tend just to sit back and listen, umm but you know if I needed to I would talk. I think the individual counselling is really good when things are acute and awful and can't see perhaps…then work your way, way through, then could perhaps go to the group. I have lots of friends and great friends, but I'm not someone who would necessarily go and join in on a group, but it was great, so supportive and the guidance we got from the facilitator". [Participant 5]

Of the eight participants who were interviewed, four had not accessed any formal support although they were able to reflect on what support they would prefer. Three of the participants suggested that one to one counselling in combination with support groups would be their preferred choice of support:

"I think for me counselling or em, either one to one kind of counselling or in a group setting. I would have benefitted along with the family to speak to other people who were going through similar things em, and I think for counselling to have that one to one interaction and maybe

just get a sense of offloading em your frustrations and the stresses of it and all I think would have been, would have beneficial". [Participant 8]

"I suppose speaking to other people about it, although maybe a lot of people wouldnae [would not] be into that because nae [not] everyone is comfortable talking in groups with people, so if there was a 1:1 service to speak to who understands". [Participant 1]

For those participants that did not access support, when discussing their experiences, all participants did appear to reflect on their situations and reported that accessing support would have been a benefit to them at some stages of their support person role:

"I would certainly look to the NHS to see, would I say I expected them to provide support for me, no. I would imagine that they would or they should be some sort of signposting, whether that's a reality or not I can't actually comment on it cause I don't know but yeah I would of, I definitely would have benefitted from group work, or you know just a group setting really and being able to hear other experiences". [Participant 2]

Of the four participants who did not access formal services three identified their preferred support choice as the National Health Service who they felt should be able to provide further information about specific services that might be able to help them as support persons in their own right. One participant described that their preference for support would be a third-party organisation and went on to explain this was due to confidentiality provisions within the third sector:

"I suppose with a third-party voluntary type group, you haven't got that same policies and that I suppose, around confidentiality, sharing information maybe? Delicate information that people don't want to be dobbing anyone in, you're concerned for your loved one and wanting to help them, but obviously you're scared that you're doing the complete opposite, that maybe you're just opening a can of worms for authorities to think that they have the right to get in about. There is a lot of stigma as well, I think that puts a lot of people off".

[Participant 2]

After the interview was finished, I noted in my field notes that they felt this was due to the National Health Service information sharing policies. They knew that when they had given information that this would be on their health records probably indefinitely for other National Health Service personnel to access.

4.15 Unhelpful support

Two participants who had experience of mental health inpatient services talked about negative experiences whereby, they did not feel included within the care and treatment of the individual they supported. Furthermore, the participants also described this further after the recording was stopped which was noted in the field notes. They provided consent for the additional information to be included in the study. Within the field notes, the participants expressed that they did not feel valued or that their opinion was taken into consideration by staff despite being the person delivering the support:

> *"I also felt isolated because the doctors, and despite the fact I was there while he was being detained, I didn't get any help or anyone say what about you, and that sort of frustrated me, so I think maybe more help at [local mental health hospital] for carers in that sense". [Participant 4]*

> *"I think when my son started at the [Substance Misuse NHS service], and I met his CPN [Community Psychiatric Nurse], and he was really good. Well, I have to say I'm not impressed with what I have seen, so that has a lot to be desired [Mental Health hospital], your just left out entirely like you don't even matter or exist". [Participant 5]*

One participant further discussed what they did not find helpful in the form of support when attending a specific alcohol support group:

> *[Talking about Alcoholics Anonymous] "You don't get any feedback. So no matter what you say they say thank you for sharing, and that's it. So I would be as well telling them, so I didn't get anything back. There were no questions on how are you coping, how do you feel. There was none of that at all, so I just have no idea how people get help from it". [Participant 6]*

The above quote could suggest that accessing a service is not enough and what makes support useful is providing a two-way dialogue. The support person's emotions become the focus. Some participants have provided some insight through suggesting that having access to an environment where it is safe and trusting to disclose their experiences and emotions, is only one part of the support. While sharing or "offloading" as some participants described it, is an important aspect, what makes this helpful is the feedback they receive and the facilitation of the session through a further enquiry and dialogue with staff members and other participants.

4.16 Future support

When discussing participants preferences for support in the future, all participants mentioned that they would find it helpful if healthcare staff had an awareness of support services available for the support person. Many participants identified this as being signposted to a specialist drug and alcohol support service for family members. They explained that this should be offered by all healthcare staff including general practitioners, specialist drug and alcohol nurses, mental health nurses and social work as often these are the individuals that they will come into contact with the most. Other participants discussed that this signposting should be to social work departments as this would help with practicalities such as financial aid and respite:

“”I have never had as much as one bit of help form services, certainly nae [not] financially. I know other carers get respite well that’s certainly never been the case for me or anyone else at the group as far as I am aware, which is completely unfair. We still help our loved ones, we still try our best, but it feels like the services just don’t care about us, we are just forgotten aboot [about]”. [Participant 7]

The quote below was representative of other participant’s experiences of National Health Service contact. All participants recognised and mentioned that they understood that the focus of appointments would generally be on the individual with the substance use issue, however, although they realised this they suggested there should be more of an awareness of how to provide help for the support person and that the value of care that the support person provides should be recognised:

“I suppose something at the start, like…we, took my son to his appointments with the NHS and while his CPN [Community Psychiatric Nurse] was very lovely, and I get that they are there to treat my son, even just to have a wee leaflet to say, here is some help for you. Like numbers or likes of ADA [local support group], websites that kind of thing, because at that time we felt very alone. I can’t quiet mind how we found ADA, but I know we had to look for it ourselves. I’m not slagging the NHS, I couldn’t do their job but hats off because someone has too…but I suppose aye..even if they asked patients about their relationships with family, that might happen I don’t know, but getting us more involved. I suppose just some more awareness that there is support for people if they want it, how you go about advertising that..I’m not sure, but it would be nice to see more rather than people having to be at their wit's end and find it themselves”. [Participant 7].

When discussing how the participants felt their needs as a support person were met the answers appeared to vary. The participants who accessed services seemed to agree that their emotional needs were attended to an extent by accessing support services. When discussing their experiences, no participants discussed any other forms of support, such as financial support, or respite services. Although some participants did mention social work involvement, this was only considered when the individuals they had supported had both a substance use issue and mental health condition.

One participant emphasised the positive impact, and practical support can have on a support person’s wellbeing within their closing statement. This participant further describes this support as life-saving and how it had a positive impact on their emotional wellbeing:

“I can’t actually remember how I found out about them…anyway, I saw someone there several times 1:1 and then I started going to the family support group. And I say they saved

my life…I don't mean physically, but I mean emotionally as they have allowed me to reclaim my life. I think there must be more awareness of carers, and I think there must be aware of the potential of carers to make a big difference. I think my son is fortunate to have my parents in law and me, so he is very lucky to have that support…many people don't have that, and he is lucky to have us. And I think there should be more acknowledgement of the role that carers can play". [Participant 6]

Another participant discussed their thanks for being interviewed and felt that research into support persons was an important thing to do to understand the role and contribution better.

"I'm glad that I suppose there are people like you out there that are you know putting the spotlight on, on this, on us. I think it is important that we do focus on the, on the person you know living with the addiction and things, but at the same time you know there's a whole, for a lot of people there are a whole other family there and friends that are trying to you know, trying to help. You know there's, I think sometimes our opinion is not really listened to or taken on. I mean it can be quite soul destroying, it's been a very difficult path and we need to be listened too".

[Participant 8].

4.17 Summary

All participants acknowledged the opportunity to discuss their experiences and felt that there needed to be further research into the experiences of their role. The participants further highlighted that services needed to have a better understanding of the positive impact that they can have and contribution to care that they make in supporting those with substance misuse issues. In this study the majority of participants felt that they had no choice but to adopt the support person role and this had an impact on their psychosocial wellbeing.

Often participants prioritised the needs of the individual they supported, sometimes neglecting their own wellbeing needs. All participants who accessed formal support described that at some stage they reached a crisis, or a point where they felt that they could no longer manage on their own. Therefore, they had to seek support from either formal support services, such as third sector organisations or healthcare professionals, or informally through friends and family. Crises were the most common catalyst for seeking help. Once the benefits of formal support became apparent to them, support persons were, on the whole, pleased with the services they received. Support persons felt healthcare workers who engage either directly or indirectly with them should recognise the benefits of support person care which improve the health and wellbeing of not only the support person but also the care receiver.

The support persons experience conveyed a sense of isolation. Some participants reported that they found the structured interview to be helpful as it allowed them to really think and reflect upon their journey mainly because they had not had an opportunity to speak about themselves before. On the whole support persons felt that the formal support they received from third sector organisations to be beneficial, as this provided a non-judgmental safe place to discuss their experiences. Preferences for support were described as the participants desire for healthcare professionals to take into consideration the needs and wellbeing of the support person in their own right. Furthermore, it was important that healthcare professionals had an awareness of services who may provide support for the participant and allow the support person to have more involvement in the individual they support's care and treatment.

CHAPTER FIVE: DISCUSSION

5.1 Overview of the chapter

This final chapter of the thesis considers support for individuals supporting people with substance use issues, the themes that emerged from the findings and the extent to which the research aims and objectives were addressed. Discussion and interpretation of the key findings is within the context of previous research and provides a discussion on both the strengths and limitations of the research methods. The implications of the research for practice are considered as well as the direction and recommendations for future research which arose from the findings of this study.

5.2 Reflection on the purpose and nature of the study

The aim of the study was to understand the experiences of support for support persons of individuals with substance use issues within the North East of Scotland, the study sought to answer the following objectives:

1) To explore the participant's experiences of being a support person for an individual with substance use disorders.

2) Explore if being a support person has had an impact on their psychosocial wellbeing

3) To explore what support, support persons utilise (if any)

4) To identify what participants preferences for support are

All participants in this study had been a support person for at least five years and self-reported when the individual they support's substance use became problematic from their perspectives. The participants were mainly comprised of woman in their middle years who were either a mother to the participant or a partner. This is comparable with the literature (Ritcher, Chatterji & Pierce 2000, Orr, Barbour & Elliot 2012 and Manthorpe, Moriarty & Cornes 2015) what is already known about the demographics of support persons for substance misuse. All participants did discuss support which differed from informal support with family and friends to a more formal structure of accessing support services although not all participants had accessed formal support. Ongoing analysis and interpretation elicited essential themes. In this regard, the findings showed areas of convergence. Experiences described illuminated the multi-faceted nature of being a support person for an individual with substance misuse issues and that support persons face an accumulation of emotions. Reduced social life, deteriorating mental health, and social isolation were key factors raised by participants.

5. 3 The realities and impacts of the support person role

As the support persons faced the prospect of becoming a carer, the nature of substance use did not allow for them to determine when this would happen. This potential change in role signifies the beginning of a change of identity which may precipitate additional lifestyle adjustments. The transition of the support person's identity from partner or parent to support person can be likened to the concept of liminality which refers to a stage where participants transition between how they previously viewed their identity as they have new characterises and identity to adapt to (Temple & Dow 2018).

The majority of support persons in this study, described their transition into the role as one into which they 'floated into'. There was little healthcare or professional input at this time and support persons were unprepared, either physically and/or psychologically, for this role. Due to this lack of choice in taking on this role, often the support persons lacked the necessary knowledge (Visa & Harvey 2019). The majority of individuals in the present study became support persons following the sudden or gradual deterioration of the individual they were supporting with substance misuse issues. Hence, most support persons took on their role in a state of 'initial innocence' (Klevan et al 2016) with no real concept of the likely realities and demands of their role. These findings are similar to those of other studies. Klevan et al (2016) for example, notes that particularly in crisis situations, the option of choice in becoming a support person is often passive. The reasons for taking on a supporting role can often be that there is no one else who can take on this role. Therefore, the support person's ability, knowledge and willingness is often taken for granted, without any form of assessment.

Support persons as a general population provide a plethora of support to their relatives ranging from personal care, assistance with activities of daily living to emotional support. Happell et al (2017 p109) argues that 'there is no single, generic support person role; rather, a supporting role emerges from prior role relationships and is influenced by values, beliefs, and life circumstances of an individual caregiver'. These authors suggest that the support person role itself changes over time and duties and tasks cannot be predicted, therefore making each caring role and experience unique.

Some participants identified that due to their support person role there were aspects of their own life which they had to sacrifice. The very act of a supporting role requires a person to accept the responsibilities and duties required of that role and when these conflict with the personal wants and desires of the person, often this can lead to prioritising the needs of others (Van der Voort et al. 2009).

Each participant described that their support person role had meant relationships with either the individual that they supported, other family members or friends had been impacted, often in a negative way. Loss of the relationship the support person once had was often described as happier times, and on almost all occasions participants would discuss this in past tense, rather than the present. Higher and disproportionate rates of self-effacement lead to increased burden and decreased marital satisfaction when the caregiver and receiver are spouses (Lam et al. 2005; Van der Voort et al. 2009). A loss, in particular, a loss of a relationship arises when we compare our current situations to those of the past, whereby we feel things, or a situation has changed to the point that we can no longer understand who we are (Thoits 2013). Many of the participants described their relationship in the past tense, describing what relationship they did have as one that had changed, often in a negative way.

Through the participant's narratives, the barriers, challenges and ultimately for some, how they have managed to cope with their journey through a changing role, was apparent. Some participants were able to describe how they had adapted, illuminating this journey through descriptions of growth and resilience. Personal growth can be defined as the internal and self-aware process whereby an individual develops talents and capabilities in response to events which can cause distress (Eisner & Johnson 2008). Furthermore, Pinquart & Sörensen (2013) claim that personal growth could develop and materialise following stressful life events, which the support persons evidently experienced.

Although five out of the eight participants were quite explicit that they did not feel that there were any positives of being a support person at all, three others reported that they did find positive aspects. All three participants described that a positive aspect was that they felt that being a support person had brought them closer together with either the individual that they were supporting or the fellow partner in the same supporting role as it allowed them to have a better understanding of their substance misuse and the consequences with their use. Within current literature it identified that alongside the well-reported aspects of carer strain, carer burden and carer needs, there was a relatively unreported component of the caring role which remained: positive aspects (Brouwer et al. 2013). A study by Cohen, Colantonio and Vernich (2002) reported that 73% of 289 caregivers of those with mental health issues were able to identify at least one positive aspect specific to their role. Understanding the perceived positive aspects of the support person role is necessary to fully understand how the support persons regard their lives and experiences as without this understanding, we would be limited to the negative aspects only, and this would be misrepresentative (Broady & Stone 2015). Positive outcomes have been identified across studies relating to those caring for the elderly and chronic illness (Hunt 2013) and those with mental health conditions (Brouwer et al 2013), reflecting that positive outcome is not limited to one particular of informal caregiver or support person.

The participants did not discuss any specific methods of coping or management of their role, but it appeared that the support they received from family members or formal groups provided an element of coping. Coping styles can vary depending on personal experience, training and personality types (Anderson 2017) but overall, those supporting a relative with substance use issues do not differ significantly in their coping styles than the general public (Lavoie 2018). Low caregiver satisfaction with their coping styles is a predictor of high burden (Lent and Otto 2018) and coping styles have been shown to positively impact on psychosocial outcomes (Shah, Wadoo & Latoo 2010).

A lack of awareness or understanding of the individual who they supports' condition has also been shown to lead to the reduced use of social support, i.e. reaching out and talking to friends or family (Anderson 2017). The knowledge and understanding of substance use by the participants in the study was mixed and generally derived from personal experience with the individual they were supporting, which would suggest that those new to the role may have higher knowledge needs.

5.4 The meaning of "support"

All participants discussed what they classed as support, was having a common understanding from fellow peers and staff. Social support is defined as the perception or experience that one is loved and cared for by others, esteemed and valued (Maskill et al 2010). During formal support the participants described the facilitation of the sessions and the feedback they received as part of the formal support sessions they attended as valuable. The participants described that although support was available through a general practitioner, or counselling services, what made support valuable was the input from others who understood their circumstances. Asking emotive questions such as how it made them feel and having others who may have been through similar circumstances, provided hope, help and a feeling of being valued. This suggests that it is not merely enough for services to provide support; this support needs to be valuable and meaningful to the individuals attending.

Support was reported to have been received by both informal and formal methods; this included friends and families and also third sector organisations. When the support persons discussed support from family members and friends, they described this as being helpful personally and indirectly through having someone to talk to honestly and openly. This was of paramount importance and required a perceived trust of the person being spoken to, such support is reported to satisfy attachment needs, improve self-worth and relieve stress (Guay et al 2017).

Both positive and negative experiences of support were described by the participants and this perspective appeared to be considered on the quality rather than the quantity of support provided. Whilst some individuals discussed that they accessed weekly services, what they found helpful was what was discussed and explored in the sessions. This provided participant's the opportunity to feel valued and listened to. The benefits of support from friends and family can, therefore, improve the support person experience, and work should be undertaken to try to enhance the psychosocial capabilities of support persons to actively seek such support to ensure these needs are met (Freidman et al 2018). Support groups can play a key role in enabling people to see themselves as a support person and as such this identity sometimes became important in making them more assertive in seeking and accepting help (Friedman et al 2018). Moreover, hearing of recovery in others was encouraging and helped understand their experiences and make sense of their emotions (Hunt 2013). The participants discussed that they felt they could discuss their experiences and despite being support persons for various different times, or supporting individuals using different substances, their experiences were very similar.

Peer support refers to the experiences that the support persons had when talking to others in the same situation as themselves (Pinquart & Sörensen 2013). For participants in this study such peers were found in friends and acquaintances who were also caregivers or through organised peer support groups. The utility of peer support was to share experiences and feel a sense of kinship through commonality (Frye et al 2008). This contrasts with support from friends, family and professional healthcare workers. Advice or support was seen as mutual rather than empathic, as understanding in peer populations is innate and lived rather than learned (Broady & Stone 2015). Orgeta, Sterzo & Orrell (2013) suggest that peer support provides only a temporary increase in satisfaction by experiencing a sense of experiential similarity. Such dissipation would suggest that peer support itself is not responsible for the longer-term benefits of social support. From the participants in this study, of those who spoke strongly for peer support talked about their experiences in the present tense indicating that they still engaged in social support, so it is not clear if the benefits of such a coping style dissipate over time in this study.

5.5 Implications for policy

It can be seen in the present study that notions of choice and control were essential to support persons, often referring to their role as an expectation by others that they should adapt to the role. The Department of Health (2018) Carers Strategy and NICE Guidelines (2017) in particular mark a 'decisive change' in policy and practice for carers or support persons. Support persons should be enabled to choose to care or not, be adequately prepared to care, to receive relevant help at an appropriate stage and be enabled to care without it adversely affecting their health. This strategy placed particular emphasis on providing support at key transition points, particularly at the beginning and end of care. The Carers Strategy highlights that the strategy should, 'support people who choose to be carers' (Department of Health 2018). This suggests that policy recognises that the transition into support giving role is a crucial phase and that when this occurs suddenly there is a need to exercise an informed choice about whether or not to become a support person. However, the findings from the present study suggest that in reality, exercising such choice and having control over the situation is extremely difficult for many support persons, with many felt that they had no choice and little control over whether or not to become the main support.

5.6 Implications for Practice

Participants in this study expressed a need for guidance and information about the potential life changes and impact on their wellbeing their role may have. NICE (2017) and Aberdeen City Health and Social Care Partnership (2018) guidelines suggest that all support persons should have access to a need’s assessment. At no stage did any support person receive any form of assessment by any healthcare or social care professional, nor was this offered. Considering the consequences and implications of supporting and individual with substance misuse issues, the support persons face a plethora of psychosocial strains which should be identified and responded to effectively (Steele, Maruyama and Glaynker 2010).

Whilst the Aberdeen City Health and Social Care Partnership (2018) make way in identifying that support persons should have a needs assessment, it is not currently something that is routinely being implemented within Aberdeenshire. Furthermore, nor does this guidance suggest who or what organisation should be conducting the carers needs assessments. An assessment tool used within some Drug and Alcohol Services, General Practitioners surgeries, Social Work and Mental Health services in England are the Carer Support Needs Assessment Tool (CSNAT) (2016) highlighted in appendix sixteen. The Carer Support Needs Assessment Tool (CSNAT) facilitates support for family members and friends (carers) of adults with long term conditions. The CSNAT Approach has five key stages: Introduction of the CSNAT assessment, identifying the carers needs, an assessment conversation, shared action plan and a shared review. The CSNAT allows for support persons to identify how much support they require, which can be as little as someone who provides active listening skills and providing information, to signposting and referring to other agencies for further support. While carer assessments specifically for those caring for individuals with substance use issues do exist, there is no standardised carer assessment identified to use nationally (ADFAM 2018).

In light of the literature and the findings within this study, it would be beneficial to develop a carers assessment to be conducted by frontline staff members who may have contact with support persons, including mental health professionals, general practitioners and social work. From the literature search and findings from this study and existing legislation including NICE (2017), it would be beneficial to carry out assessments to gain insight into the individual's knowledge and understanding of substance misuse, determine if there is any impact on the relationship between support person and care receiver, any concerns regarding physical and psychological wellbeing and effects on daily life. This assessment tool would be able to provide support persons with an overview of their needs and allow staff to signpost and/or refer to relevant services to help the support person manage both their role, and their wellbeing.

Regarding collaboration with healthcare professionals, the participants acknowledged their own experience and expertise in the care and support of their relative and felt underutilised when care and treatment was being planned. The variance in care provision without the support person understanding why, can increase strain further and reduce locus of control (Quinlan, Deane & Crowe 2018). Such adverse effects can be avoided with an explanation of the mode of treatment to support persons so that the support they provide for their relative can be congruent and informed (Sadler & McKevitt 2013). These effects should be considered regarding the inclusion of support persons in the care and decision making for their relatives despite the challenges of confidentiality, as feeling excluded or ignored by healthcare workers can lead support persons to feel isolated, powerless and frustrated (Wilkinson and McAndrew 2008). The insights that support persons have, not just in regard to their own experiences, but to the care and wellbeing of the individual who they support should be considered with higher regard by healthcare professionals. However, all participants in this study stated that this was not the case. Most participants described their dealings with healthcare professionals as being negative, often feeling disregarded and excluded from not only the individual they supported, but their own wellbeing not being taken into consideration.

Support person concerns tended to concentrate on apprehensions of what their care recipient was doing if they were not with them such as engaging in risk-taking behaviours. They also expressed worries about what they would do if they were no longer able to provide care for them. Participants interviewed in this study who reported the fear of what would happen to their relative in their absence were parent caregivers and the eldest of the spousal caregivers. This could suggest that such worries increase with age given increased awareness of one's finitude and mortality are associated with age (Van Boekel 2013). De Coster (2017) also found that caregivers worried most about who would look after their relative if they were no longer able. This would indicate that support persons who are older or more mindful of their finitude may be more inclined to worry and would require greater assistance regarding this. Thus, putting contingency and anticipatory care plans in place with support persons could help ease this concern.

A significant concern that predominated the support person interviews was the unpredictability of the substance use. Concern arose around care receiver behaviours that could be self-harming or destructive. This was challenging for the support person who felt unable to determine when these behaviours would arise so they worried about when and if they would use substances. Further understanding of behaviours and triggers of substance use may be of assistance to enabling support persons to feel more informed about the possibilities of such behaviour and utilise this information in coping (Van Boekel 2013). This unknown and unpredictability of substance use leads to increased levels of stress, anxiety and strain that will continue to exist, as these feared outcomes are constantly upheld against the passing of time as 'something that might happen' (Rowe 2012).

Support persons in this study reported that they received little to no information about the individual who they support and their drug use or when they were admitted to hospital. Support persons commonly addressed the shortfall in information by obtaining additional information through online sources. The lack of involvement in decisions was a source of frustration, as support persons in this study thought they could contribute saliently through sharing detailed knowledge about the life of the individual that they supported, provide a deeper insight into the substance use and improve communication between health professionals and family members

Support person involvement in the care and treatment has been recognized as an integral component of mental health care, including substance use services (Gray et al 2009). The increased emphasis on carer participation has to some extent been driven by the shift away from hospitals towards primary care providing mental health treatment in the community. Wrosch, Amir & Miller (2011) discuss the relative failure to support family carers adequately is through the notion of 'community care is family care', with the presence of a supportive family member, particularly a spouse or partner, often being essential to maintaining morale and positive adaptation.

Mental health professionals often express interest in collaborative decision making, however, health professionals commonly state that they do not include mental health consumers in decisions because of a perceived lack of capacity (Knowles et al 2016). The findings of the present study demonstrate that exclusion from decision making also extends to carers of those with mental health issues, who have the right to be involved in decision making and arguably have the capacity to make worthwhile contributions. Hence, mental health services may need to reassess the extent to which carers could be more effectively included in decision-making, care and treatment of substance use services.

5.7 Strengths and limitations

There were both strengths and limitations of this study which are worthy of consideration. Strengths of this study lie in a better understanding of the experiences of those who were, who have become, or remain, support persons and the findings provide in-depth information regarding the challenges of this role. Key strengths of the study were the use of qualitative description to illuminate the experiences of support and provide a voice for a range of support person relationships. Furthermore, the flexible nature of the interviews allowed the development of thoughts; and positive feedback received from the participants.

The limitations lie in the difficulties of recruitment, which restricted the range and number of support persons who took part. The sample size was small with eight participants in one geographical location. Whilst the recruitment of participants was difficult, it is important to note that the experiences of the eight participants who agreed to participate reported very similar experiences, emotions and concerns. The individuals who were willing to participate may be individuals who find it easier to verbalise and articulate their experiences or may be particularly passionate about talking about their experiences. It should also be recognised that ex-support persons could potentially possess different experiences and insights than those who remain in the role. This study recruited participants who the majority worked within the healthcare profession. This may suggest that individuals who may have had exposure to research studies in the past may be more willing to contribute to a research project.

5.8 Recommendations

This study provided insight into the experience of support for support persons caring for those with substance misuse issues, however, there is the potential for this to be researched further. Healthcare professionals are committed to involving family and carers in care and treatment of patients, however this study has identified the reality of how involved carers and family members are, can be disputed. It would be of interest to investigate healthcare practitioner's perceptions of support persons input and contribution to the care and treatment of the care receiver. Furthermore, this study has further highlighted what support persons find valuable, and helpful and it would be of benefit for all sectors and not just third sector agencies, to have an awareness of these findings and what meaningful support is to the support persons.

5.9 Conclusion

Support persons provide care and support to the individuals they care for often at the expense of their own well-being. The participants in this study highlighted the reasons why they may become a support person, and often there is little choice in this. Despite this lack of choice, the support persons adapt, adjust and commit to their role, often without any support from services or others. The reasons for this were noted to be due a number of factors. The first was due to the support persons wanting to help the individual they supported on their own and explaining that there was embarrassment and stigma around telling others about their circumstances. Often many of the participants reached a stage where they were unable to manage on their own and needed support for themselves. This support varied, from informal support persons including close friends and family, and for some this was enough to be helpful. However, for others they accessed formal support in the form of Health services, carer organisations and specialised drug and alcohol family support services. The support received varied and often were accessed at a point of crisis.

All support persons spoke highly of the specialist drug and alcohol services which they had accessed. This appeared to be for a few reasons. The first was it was a place of safety to disclose the support persons intimate feelings and circumstances to people who understood their experiences, non-judgmentally. Although efforts have been made through new legislation which seeks to empower support persons and is a positive step towards acknowledging the contribution, they make to the care of individuals with substance misuse issues, there are areas it does not address. This study has conceptualised the complexity of support persons roles and provided insight into what support means to them, what is helpful, unhelpful and hopes for the future. Thus, in order to meet the needs of support persons more effectively, service providers should tailor support across the entire span in the support person trajectory. By assessing the needs, preferences, skills and expertise of support persons, this can empower them, facilitating the continuance of support giving.

5.10 Reflections from researcher’s perspective

In October 2017 I commenced my studies and masters by research journey. The process of undertaking this research study has resulted in a variety of feelings and emotions, relating to my own skills and ability. When I reflect back on my studies, I can see that I have gained new knowledge and skills pertaining to literature searching, critical appraisal and research methods amongst many others. At times, the writing up process has been a real challenge and on regular occasions caused me to question my own abilities. Fortunately, my passion for substance use and family members has remained of interest throughout, helping me to persevere and get to this stage. At the outset of my studies, I believed that I would be able to provide the answers to all my questions regarding the support person’s experience. However, I now realise that I was somewhat naive and can accept that undertaking a research study at this level often only generates more questions which need to investigate or studied further.

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Appendix One- Search Strategy

My research questions:	1. What service support exists for support persons supporting individuals with substance misuse issues? 2. What is the impact on psychosocial wellbeing of support persons? 3. What preferences for support do carers have, and are these preferences being met?
Places to search for information:	This Literature review will be conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement. The following electronic databases will be included within the search architecture; MEDLINE (Ovid), CINAHL (EBSCO), ASSIA (ProQuest), Embase, NHS Knowledge Network, PsycINFO (Ovid), Web of Science.

List of sources searched:	Date of search	Search strategy used, including any limits	Total number of results found	Comments
Cinahl	23/10/17	Substance misuse **AND** carers – search saved in Refworks	9	Individual Titles and abstracts read and screened – 8 discounted on title screening – 1 paper full text for screening *1.Supportive Practice with Carers of People with Substance Misuse Problems.*
Ebsco	23/10/17	Substance misuse **AND** carers **OR** caregivers **OR**	54	Individual Titles and abstracts read and screened – 1 duplicate 50 discounted on title screening and 3 papers screened for full text

		family members **OR** relative search saved in Refworks		*1.Family members affected by a relative's substance misuse looking for social support: who are they?* *2. Use of a structured brief intervention in a group setting for family members living with substance misuse.* *3. Family interventions for drug and alcohol misuse: is there a best practice?*
Cinahl	04/11/17	Substance addictions AND carers OR caregivers OR Family Members	18	Individual Titles and abstracts read and screened *- No relevant titles or abstracts*
Cinahl	06/11/17	Carers AND substance use - search saved in Refworks	22	Individual Titles and abstracts read and screened - 1 duplicate, 18 discounted on title screening *1. Carer involvement with drug services: a qualitative study.* 2. *Promoting family-focused approaches within adult drug services: The potential of the 'Senses Framework'* *3. The Association Between Substance Use and the Needs of Patients With Psychiatric Disorder, Levels of Anxiety, and Caregiving Burden*

<table>
<tr><td>My research question:</td><td colspan="4">1. What service support exists for support persons supporting individuals with substance misuse issues?
2. What is the impact on psychosocial wellbeing of support persons?
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<tr><td colspan="5"></td></tr>
<tr><td>List of sources searched:</td><td>Date of search</td><td>Search strategy used, including any limits</td><td>Total number of results found</td><td>Comments</td></tr>
<tr><td>Cinahl</td><td>08/11/2017</td><td>Carers AND substance use disorder OR substance abuse Or Drugs OR addiction</td><td>525</td><td>Individual Titles and abstracts read and screened – 3 duplicates 520 discounted through title and abstract screening
<i>1.Family Functioning and Quality of Life among Families in Eating Disorders: A Comparison with Substance-related Disorders and Healthy Controls.</i>
<i>2. Users, carers and professionals' experiences of treatment and care for heroin dependency: Implications for practice.</i>
<i>A preliminary study</i></td></tr>
</table>

Cinahl	09/11/2017	Carers **OR** caregivers **OR** family members **AND** substance misuse use disorder **OR** substance abuse **OR** drugs **OR** addiction	2	Individual Titles and abstracts read and screened *- No relevant titles or abstracts*
Cinahl	10/11/2017	Carers **OR** Caregivers **OR** family members **AND** substance use disorders **OR** substance abuse **OR** Drugs **OR** addiction **OR** psychosocial	321 – limited by adult carers = **167**	Individual Titles and abstracts read and screened – 7 duplicates. 557 titles and abstracts screened however not relevant to current lit review *1.Satisfaction of workers, users and families of psychosocial care centres in alcohol and other drugs* *2.Characteristics of family caregivers and drug users* *3. Behavioural family counselling for substance abuse: a treatment development pilot study.*
Cinahl	11/11/17	Substance abuse AND carers OR caregivers OR family members 1989-2017	113 – reduced search to Adult as many search titles where coming back with adolescent = **41**	Individual Titles and abstracts read and screened – 235 discounted through title and abstract as not focused on question or relevant to lit search. 6 full texts read – 1. *Challenges and opportunities to integrating family members of injection drug users into harm reduction efforts within the Atlantic Canadian context* 2. *A 5-step intervention to help family members in Italy who live with substance misusers* *3. Predictors of burden of family caregivers of women with substance use disorders or co-occurring substance and mental disorders.* *4. Predictors of depressive symptomatology in family caregivers of women with substance use disorders or co-occurring substance use and mental disorders.* *5. The impact of a substance abuse disorder on the well-being of family*

				caregivers of adults with mental illness. *6. Data collection with family caregivers of dependents of illicit psychoactive substances: experience report*

Appendix Two: Data Extraction Sheets

Author	Aim	Design	Demographics	Key Findings	Limitations
Biegel et al (2007)	**Aim:** Examine the impact of having a female family member with substance misuse on family caregivers. **Context:** Predictors of subjective burden and objective burden on caregivers and on types of burden were explored. **Country: USA**	**Sample size**: 82 woman receiving substance misuse programmes and their family member providing more social support. **Sampling:** Purposive **Response rate:** 96% **Design:** Cross sectional	**Demographics: Age:** 18 to 77 years, with a mean age of 40.04 years (SD = 13.59). **Marital Status:** Half of the caregivers (50.0%) were never married; 24.4% were divorced/separated; 22.0% were married; and the remaining 3.7% were widowed. **Ethnicity**: 84.1% of the caregivers defined themselves as African American, 12.2% as Latino, and 3.6% as other. **Education:** More than third (37.8%) of the caregivers worked full time, 22% worked part time, and 29.0% were unemployed. **Carer group:** Unlike caregivers for other populations, a large proportion, 40.2%, were male and 59.8% female. Almost onethird (31.7%) were the significant other of the care recipients; the remainder were either a sibling (23.2%), parent (19.5%), child (11.0%), or other relative (14.6%). **Type of drug use:** Unknown	Over half (56%) of family caregivers indicated that they were unlikely to ask others for help in providing support for their care recipient. Almost half (48%) of family caregivers had no contact with their relative's treatment provider during the past six months. The degree of caregiver burden varied by burden type. As a group, caregivers in this sample experienced moderate levels of worry and displeasure, and lower levels of stigma and impact.	The sample in this study of lower socioeconomic women, primarily African American, from the Midwest, limits its generalizability to similar populations. In addition, generalizability of study findings is also limited to the specific psychiatric disorders studied. Although this study was theoretically based, its cross-sectional design limits causal inferences. Unknown what type of substance has been used from the care receiver, which may have changed or looked more in depth at what specific substances were being used and if there were any differences in results.

Copello et al (2008)	**Aim:**. Two validated and standardized self-completion questionnaires measuring physical and psychological symptoms of stress (Symptom Rating Test) and behavioural coping (Coping Questionnaire) experienced by the family members. **Country: England**	**Sample size**: 143 **Sampling:** Purposeful **Response rate:** Unknown **Design:** Randomised Control Trial	**Demographics:** Unknown **Age:** Unknown **Marital:** Unknown **Status:** Unknown **Ethnicity**: Unknown **Education:** Unknown **Carer group:** Unknown **Type of drug use:** Unknown	Two validated and standardized self-completion questionnaires measuring physical and psychological symptoms of stress (Symptom Rating Test) and behavioural coping (Coping Questionnaire) experienced by the family members. It was predicted that the full intervention would show increased reduction in both symptoms and coping when compared to the brief intervention.	No differences were found, however, between the two arms of this trial. This finding suggests that the brief intervention was associated with similar changes in the main outcome measures; namely, family members' symptoms and coping behaviours when compared to the full intervention

Li et al (2014)	**Aim:** Examined the preliminary outcomes of an intervention targeting IDU's and their family members in Vietnam. **Country:** Vietnam	**Sample size**: 83 **Sampling:** Purposefully **Response rate:** 78% **Design:** Feasibility	**Demographics: Age:** **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** All of the family members in the standard care group and 81.4% in the intervention were women (*p*= 0037). About 40% of the family members were spouses, 33.7% were parents, and 12.0% were siblings. Family members in the intervention group were younger (*p* _ .0375) and less likely to be unemployed (*p* _ .0031) than those in the standard care condition. Family **Type of drug use:** One fourth (*n* _ 23, 27.7%) of IDUs reported excessive alcohol drinking during their lifetime. Heroin was the primary substance abused by all participants; two participants reported cocaine use, one reported amphetamine use, and two reported cannabis use in their lifetime. Two (2.4%) participants reported using more than one substance per day during their lifetime. Half (*n* =20, 50.0%) of the IDUs in the standard care and 26 (60.5%) in the intervention group reported 10 years or longerhistory of drug use.	No significant difference was observed in attrition rate between the intervention conditions. In Vietnam, families play an important role and exert the most important contextual influence in the lives of IDU's (Go et al., 2011). Most IDU's have daily family contact or live in their parents' home, so the family is the principal source of support for IDU's	The sample size was small and the follow up period was short – therefore the study results did not provide conclusive evidence of the interventions efficacy. Due to the small sample size, there were also some imbalances in background characteristics were found between intervention conditions. The outcomes relied on self- reported data.- so issues of bias could be raised. Lack of control activity provided to the standard care group, so it is difficult to differentiate

Manthorpe, Moriarty & Cornes (2014)	**Aim:** A study of carers workers and family carers undertaken in four areas in England. **Context:** Family members and workers of family members in four areas in England. **Setting:** Support groups- third party and recruited from Social work caseloads. **Country: England**	**Sample size:** Interview participants consisted of: local authority commissioners or funders responsible for planning support for carers (n = 8), representatives of voluntary organisations supporting carers or disabled people (n = 16), carers' workers (n = 38) and family carers (n = 24). And purposefully sampled. **Sampling:** Purposefully **Response rate:** Unknown **Design:** Qualitative 1:1 structured interviews	**Demographics: Age:** Unknown **Marital Status:** Unknown **Ethnicity:** Unknown **Education:** Unknown **Carer group:** n= 24 family carers **Type of drug use:** Unknown	Found that carers of individuals with substance misuse issues were most likely to report that they found it very difficult to find information about social care services. Very few surveys returned by local councils identified work with carers supporting people with substance misuse problems as a priority area in which they provided or sought to develop, support for family carers. Almost all carers stated they felt under recognised in terms of access to support for carers or as a problem that made existing health conditions in the person being cared for far more complex to support.	This study is limited, in that it was not funded specifically to look at carers of people who misuse substances and it is based on others' perceptions of the role that social workers could play in supporting this group of carers and not social workers involved in direct work with carers of people with substance use disorders. Limited demographic information. Little is known about influence of demographic variables on needs or preferences of support

MacMaster (2008)	**Aim:** The central concept of this framework is that the existence of mental illness and substance abuse in any family member serves as a source of stress to the family caregivers, which in turn has an impact on their well-being. **Country:** USA	**Sample size**: 110 **Sampling:** unknown **Response rate:** unknown **Design:** Exploratory, Non experimental cross sectional	**Demographics: Age:** The average age of the sample was almost 60 years (m = 59.3**, SD := 12.3). Marital Status:** Unknown **Ethnicity:** Respondents primarily identified themselves as Caucasians (98.2%), **Education:** unknown **Carer group:** female (72.5%),and living alone or with their spouse (62.3%). The sample of family caregivers was made up of persons who were a member of a support group in two cites, one in the Midwest and one in the Southeast, for family members of persons with mental illness and who provided social support to their relative (biological, marital or adoptive relationship) with a relative with mental illness. **Type of drug use:** unknown	Based on the work of Biegel, Sales & Schulz. As a group, reported a positive level of social support. However, found that agreed least with the question- if the caregiver was sick, that they could find someone to help look after the care receiver. On the question asking if they felt that they received enough support from: family, friends, neighbours and professionals- indicated that they felt they received slightly less than enough support from the four groups. 34.3% were identified of developing clinical depression for their answers on the clinical depression scale. Despite the differences found in symptomology and perceptions of caregiver burden, the presence of substance use had limited impact on the physical and emotional wellbeing of family caregivers overall.	Based on a cross- sectional design and casual inferences cannot be made from the data. Relied heavily on participants were asked to self-report on their own and care receivers mental health and substance use. Looked at both mental health and substance use.

Orr, L, Barbour, R, & Elliott, L (2013)	**Aim:** To explore the purpose and scope of carer involvement with adult drug services in north east Scotland **Context:** Family carers in Dundee area **Setting:** Recruited through drug services, advertising in local community centres and snowball sampling. Individual interviews **Country: Scotland**	**Sample size**: n = 20 **Sampling:** Purposefully **Response rate:** Unknown **Design:** Qualitative	**Demographics:** **Gender** n = 19 female, n -= 1 male **Age:** Average 40-59 **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** 18 where parents, 1 aunt, 1 sister **Type of drug use:** Unknown	Three themes represented in the data Current levels of involvement, use of the term carer and opportunities to change. Most criticisms where in regards to primary care and drug treatment services. Majority of services where sourced nationally rather than locally. 5 Carers out of 20 felt satisfied and felt that they benefited from local service support. 1- NHS counselling service, 2- Social Work teams and 2 third sector organisations. 5 carers reported sporadic support. All carers reported that they wanted more services for drug users and for themselves. Separate services may allow for more opportunities to share their concerns and frustrations, however there they should be given a choice.	No identification of what drugs were used, therefore unable to identify if there were any differences in experiences of support.

Sakiyama et al (2014)	**Aim:** Explore experiences of support of affected family members dealing with substance misuse issues. **Context:** Brazilian affected family members. **Setting:** Support groups "Amor Exigente" adapted from the American support group "Tough Love" **Country:** Brazil	**Sample size:** n=50 **Sampling:** Convenience **Response rate:** No reported. **Design:** Cross-sectional survey	**Demographics: Age:** 28.4 (SD 10.0) years. **Gender:** Male 91% (n NR), female 9% (n NR). **Marital Status:** NR **Ethnicity:** NR **Education:** NR. **Socioeconomic:** NR – narrative majority high socioeconomic class **Carer group:** 67.6% parents of a substance misusers, 11.0% spouses, 8.6% siblings, 4% grandparent, 4% Uncle/Auntie, 2.8% boyfriend/girlfriend, 2.0% offspring. **Type of drug use:** 67.6% cannabis, 64.2% cocaine, 47.6% alcohol, 38.8% crack cocaine (typo graphical error in original paper, additionally combined substance misuse not reported.)	It took approximately 3.7 years for the AFM to discover about their relative's substance misuse. Approximately, 43% reported seeking support when they discovered a relative's substance misuse, 58% reported it took 2.6 years to seek support. Reasons for not seeking support included: belief that the substance use problem was transient and would resolve without help, they did not know where to get support, and the substance use relative did not allow the AFM to seek help. 35.8% sought support from healthcare professions (doctors, psychologists) or 33% from support groups	No demonstrated reliability or validity in the study questionnaire. Potential for selection bias. No prospective follow-up. Lack of statistical analysis. Limited demographic information. Little is known about influence of demographic variables on needs or preferences of support.

Slaunwhite et al (2017)	**Aim:** Assessed the emotional health of caregivers by care-receiver condition type (i.e. mental health or addictions vs. physical or other health problems), levels of caregiver stress and methods particularly for reducing stress among caregivers of persons with mental health or addictions disorders. **Context:** Carers of individuals with mental health and substance use disorders in 10 provinces in Canada. **Country:** Canada	**Sample size**: 28,716,204 Canadians residing in 10 Canadian provinces. **Sampling:** The sampling technique ensured that all respondents that identified as a caregiver or care-receiver completed the long version of the survey, whereas non-caregivers or care-receivers were randomly assigned to a short- or long-form questionnaire (Statistics Canada 2013). **Response rate:** 65.7% **Design:** Cross sectional	**Demographics:** **Gender:** 64% Female, 35% Male **Age:** Mean age 48 **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** 8% spouse, 18.6% Son/daughter, 22.9% parent, 13.2% sibling, 13% other family member, 24.4% Friend/neighbour **Type of drug use:** Unknown	Caregivers of persons with mental health or addictions problems reported much higher levels of stress and were significantly more likely to report that caregiving had a negative impact on their emotional health The most significant forms of stress for caregivers of persons with mental health or addictions issues were managing their own emotions (OR = 1.47, P = 0.001); finding services for the care receiver (OR = 1.62, P = 0.002); and getting along with care-receiver or managing care-receiver's mood (OR = 2.72, P = 0.001). Caregivers of persons with mental health or addictions problems were significantly more likely to report that they felt tired (OR = 1.87, P = 0.001); worried or anxious (OR = 1.91, P = 0.001); overwhelmed (OR = 2.26, P = 0.001); lonely or isolated (OR = 1.87, P = 0.001); short-tempered or irritable (OR = 2.27, P = 0.001); resentful (OR = 1.97, P = 0.001); and that they had experienced loss of appetite (OR = 1.85, P < 0.001) or disturbed sleep (OR = 1.68, P < 0.001) because of their caregiving responsibilities.	Does not include households without landline telephones. Due to the belief that because of the common experiences in caregiving and the small group sample sizes, mental health or addictions caregivers were combined into one category for data analysis. The survey participants were not asked to identify the type, length or nature of their care receivers mental health or substance use, which limits the genarisability of findings. Participants were asked to self-report the care receiver's illness, which could be inaccurate based on their willingness to share information about the care receivers health status. Given that it is cross- sectional It is possible that caregivers reported stressors are indirectly due to factors linked to care receivers such as hereditary and the environment.

Templeton (2009)	**Aim:** *Use of a structured brief intervention in a group setting for family members living with substance misuse.* **Country:** England	**Sample size**: 12 **Sampling:** purposeful **Response rate:** Unknown **Design:** Feasibility study	**Demographics: Age:** **Marital Status:** NR **Ethnicity:** NR **Education:** NR **Carer group:** NR **Type of drug use:** NR	Quantitative Data from participants and qualitative from the staff members. Interventions fall into 3 categories: • Working with family members to facilitate engagement and maintenance of user into treatment. • Joint work with user and family member, but with a focus on outcomes specific to treatment/consumption. Supporting family members directly and in their own right	However, it is possible that the data collected are biased towards family members who are more stable, at least in terms of engaging with a service, and who are also possibly more motivated/ready to change. Further data from a range of other carers, and from a far larger group of carers who engaged with the service, would be necessary for any further level of weight and interpretation to be placed on these findings.

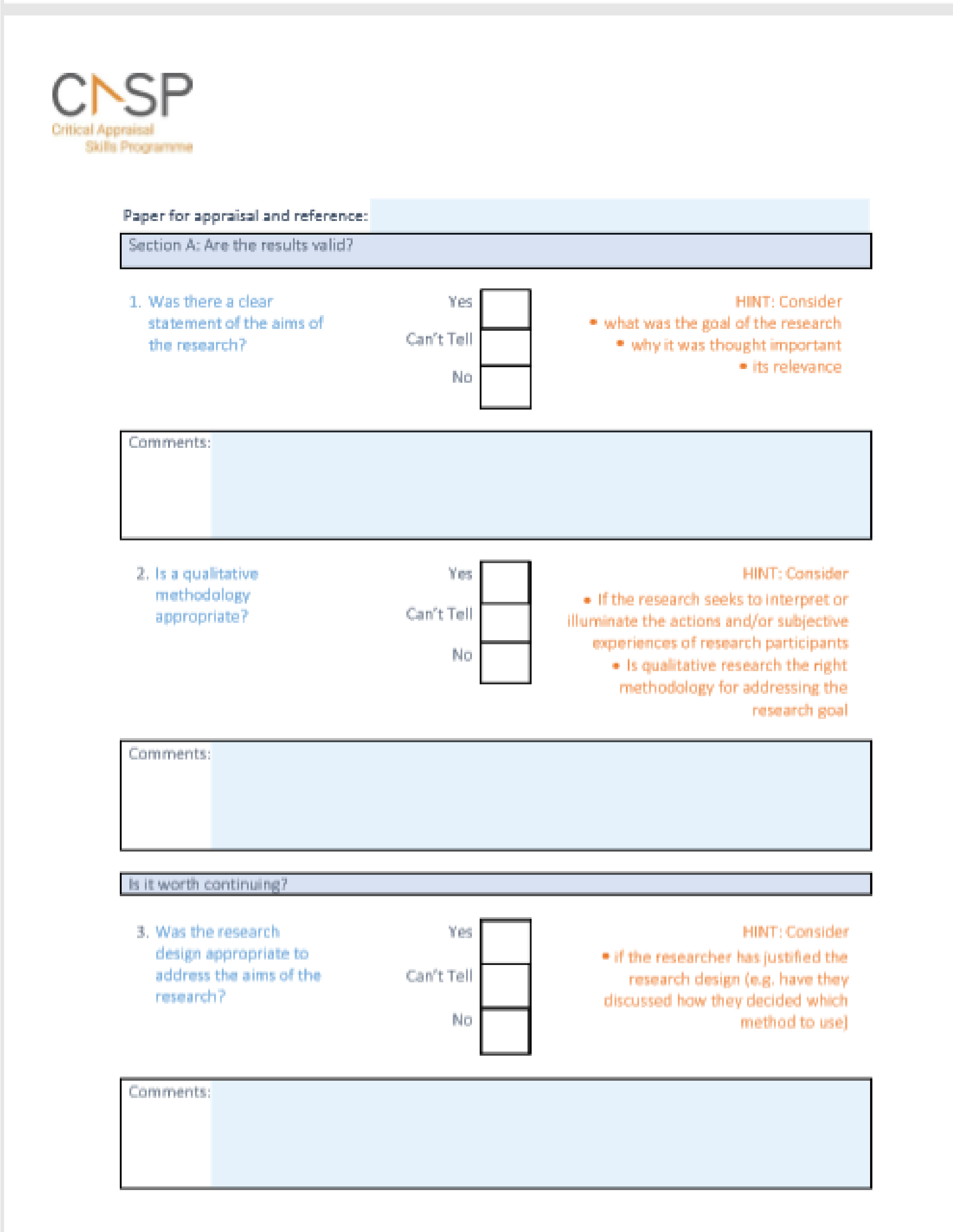
Velleman et al (1993)	**Aim:** Interview relatives of substance use disorders with the identification occurring through clinics and self-help groups. **Country:** England	**Sample size**: 50 **Sampling:** purposeful **Response rate:** Unknown **Design:** Mixed methods	**Demographics: Age:** **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** 28 partners (19 female, 9 male), 19 parents (11 mothers,8 fathers) 2 sisters, 2 brothers, 1 daughter. **Type of drug use:** Of the 50 families, 10 involved partners (5 male, 5 female) who were cohabiting with a user of prescribed minor tranquillizers, whereas all 40 other families involved relatives of users of a variety of illicit drugs (with opiates being the major drug in 14 cases, amphetamines in 19, and polydrug usage in 7). We included both prescribed opiates and illicit use of tranquillizers within the 'illicit' group.	Support that relatives received, 88% received some form of support. 74% received informal support, (family, friends, work colleagues, clergymen) 60% received formal support (professional, agency, such as drugs advice service, community drugs team, GP, CPN, Psychologists and self help support). Therefore high percentage of carers received one or more method of support. Although views had been noted to be negative, 74% were able to remain hopeful for the future. The type of drug which the respondent's relative was using led to very little difference in carers attitudes. Despite receiving forms of support 42% stated the support they did receive was not helpful. Large numbers of these relatives reported physical violence towards themselves (50%), unpredictable behaviour (42%), stealing from family members (42%), being lethargic in one way or another (either in bed; 36%, or generally; 26%), and behaving in an embarrassing way in front of others (38%)	One limitation of research of this kind is the lack of a control or comparison group. Large percentages of the family members of problem drug users who were interviewed reported many negative events, and many corresponding negative effects on both their feelings and behaviour. What is not known is the percentage of families drawn at random from the general population who would equally report violence, unpredictable behaviour, lethargy, etc.; or negative feelings about their partner or offspring.

Velleman et al (2008)	**Aim:** Conduct a feasibility study, testing whether a intervention successful in the UK, aimed at helping family members of people with alcohol or drug problems (the 5-Step Intervention), would also be applicable in Italy. **Country: Italy**	**Sample size**: 52- 10 lost in follow up = 42 **Sampling:** Unknown **Response rate:** Unknown **Design:** Feasibility study	**Demographics: Age:** mean age of all participants was 46 years (range, 18 – 80). **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group: *Forty-seven*** out of the 52 family members recruited were ***female*** (90%), people were mothers (21, 40%) and female partners (20, 38%), with 3 sisters, 3 daughters. Males were heavily underrepresented, with there being only 4 fathers and 1 brother, and no male partners. **Type of drug use:** Of these, FMs stated that 18 users (35%) used only alcohol, 28 users (54%) used only drugs, and 6 users (11%) used both alcohol and drugs in combination. Eighteen users (35%) were either polydrug users or used both one main drug plus alcohol, with 34 users (65%) restricting themselves solely to one main drug or solely to alcohol.	It is feasible to deliver this intervention in Italy. Materials were successfully translated and Back-translated and were deemed relevant for an Italian context; different health services organizations and their staff were recruited to participate; 52 family members were recruited and received the intervention. Before-and-after comparisons of these family members' physical and psychological symptoms, and their coping methods, showed that major and significant changes were made during and following the intervention. It can be seen that FMs symptoms (physical, psychological, and total symptoms) and their tolerant-inactive coping mechanisms all changed in statistically significant (and positive) ways over the course of the intervention.	The types of help and treatment on offer include methadone supply, day services and community treatments; but there are no specific interventions oriented towards or directed at family members, neither preventive programmes or intervention ones.- may have different results as services providing support are slightly different to how UK based services operate.

Velleman et al (2011)	**Aim:** The trial compared two brief interventions for use by primary health care professionals with family members (FMs) affected by the problematic substance use of a close relative. **Country:** England	Sample size: Follow up was conducted from oro-*143 family members* who received one of the two interventions described in Copello et al. (2009) - *51 of whom received the full intervention and 92 the brief intervention.* Twelve-month data were obtained from 90 (63%) family members at *12 months, 32 (63%) from the full intervention arm, 58 (63%) from the brief intervention.* **Sampling:** Purposeful **Response rate:** Unknown **Design:** Randomised control trial	**Demographics: Age:** **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** Eighty-five per cent of the family members were female, the family members' mean age was 45, 52% were partners of a substance misuser, 35% were parents to a substance misuser, 6% were adult children and 6% were related in other ways (e.g. grandparent, aunt, etc.). **Type of drug use:** Sixty per cent of the family members reported that their relative primarily misused alcohol, 40% drugs. Family members reported having lived with the misuse problem for a mean of 9 years.	Shows that there were still no significant differences at 12 months between the two interventions. *At 12 months, 50/89 (56%) thought things were much or a bit better; 21 (24%) saw no difference, and 18 (20%) though that things were much or a bit worse in terms of family dynamics.* The data shows that there are differential amounts of symptoms, with the 28 (at 12-months follow-up) family members whose relative had a drug problem demonstrating greater symptom levels than did the 45 whose relative had an alcohol problem, and with the six family members whose relative had both alcohol and drug problems showing the lowest levels of symptoms.	***"These five steps can all be undertaken within one session, but more usually they are undertaken over a number of sessions"*** – It states that the 5 step/brief intervention has been utilised for 5 sessions, but no justification as to why only 5 or reasoning as to why this particular number of sessions has shown to be effective/if at all. ***"Twelve months after the start of an intervention has become a relatively standard follow-up period within a wide range of studies (e.g. Kelly, Halford, & Young, 2000, who examined an intervention delivered to women with drinking problems and marital distress; Heather, Robertson, MacPherson, Allsop, & Fulton, 1987, who used a self-help manual based on behavioural principles to help problem drinkers) and that was the length used in this study"*** One study which being very outdated from 1987, no evidence provided that this has been used effectively for carers.

Ritcher, Chatterji & Pierce (2000)	**Aim:** The aim was to qualitatively examine how Al anon members, describe their experiences living with an individual with substance misuse issues. **Country:** USA	**Sample size**: 11 **Sampling:** Purposeful **Response rate:** unknown **Design:** Qualitative 1:1	**Demographics: Age:** **Marital Status:** Unknown **Ethnicity:** unknown **Education:** unknown **Carer group:** unknown **Type of drug use:** Alcohol	Identified into themes: Early signs of substance misuse- Most could not identify a particular event or time when they realized that their partner had a issues with substances. – most reflected that in retrospect there had been signs the individual had issues, they just did not recognise it at the time. All respondents stated they were embarrassed and felt they had low self-esteem. All respondents felt that the substance misuse had a huge impact on their own wellbeing in a negative way.	The results presented are based on a limited number of interviews with a select group of family members. More specifically the interviews were restricted to those members from Al Anon who they clearly found beneficial and had been attending for a long time. Therefore, it may not be an overall representation to the individuals who may not have found it helpful.

Appendix Three- CASP Appraisal Tool- Qualitative



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

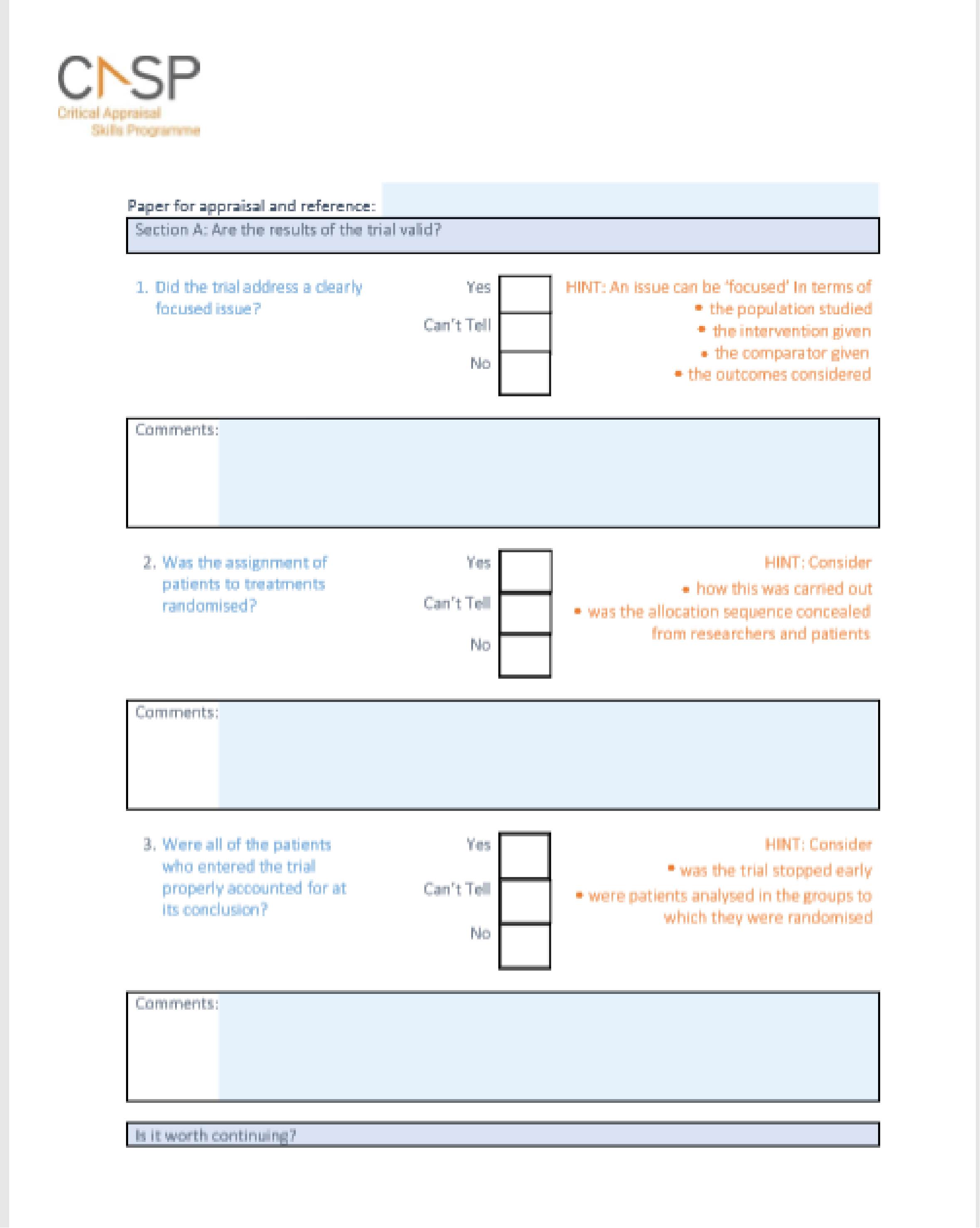
3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

Appendix Four- CASP Appraisal tool- Randomised Control Trial



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results of the trial valid?

1. Did the trial address a clearly focused issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: An issue can be 'focused' In terms of
- the population studied
- the intervention given
- the comparator given
- the outcomes considered

Comments:

2. Was the assignment of patients to treatments randomised?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- how this was carried out
- was the allocation sequence concealed from researchers and patients

Comments:

3. Were all of the patients who entered the trial properly accounted for at its conclusion?

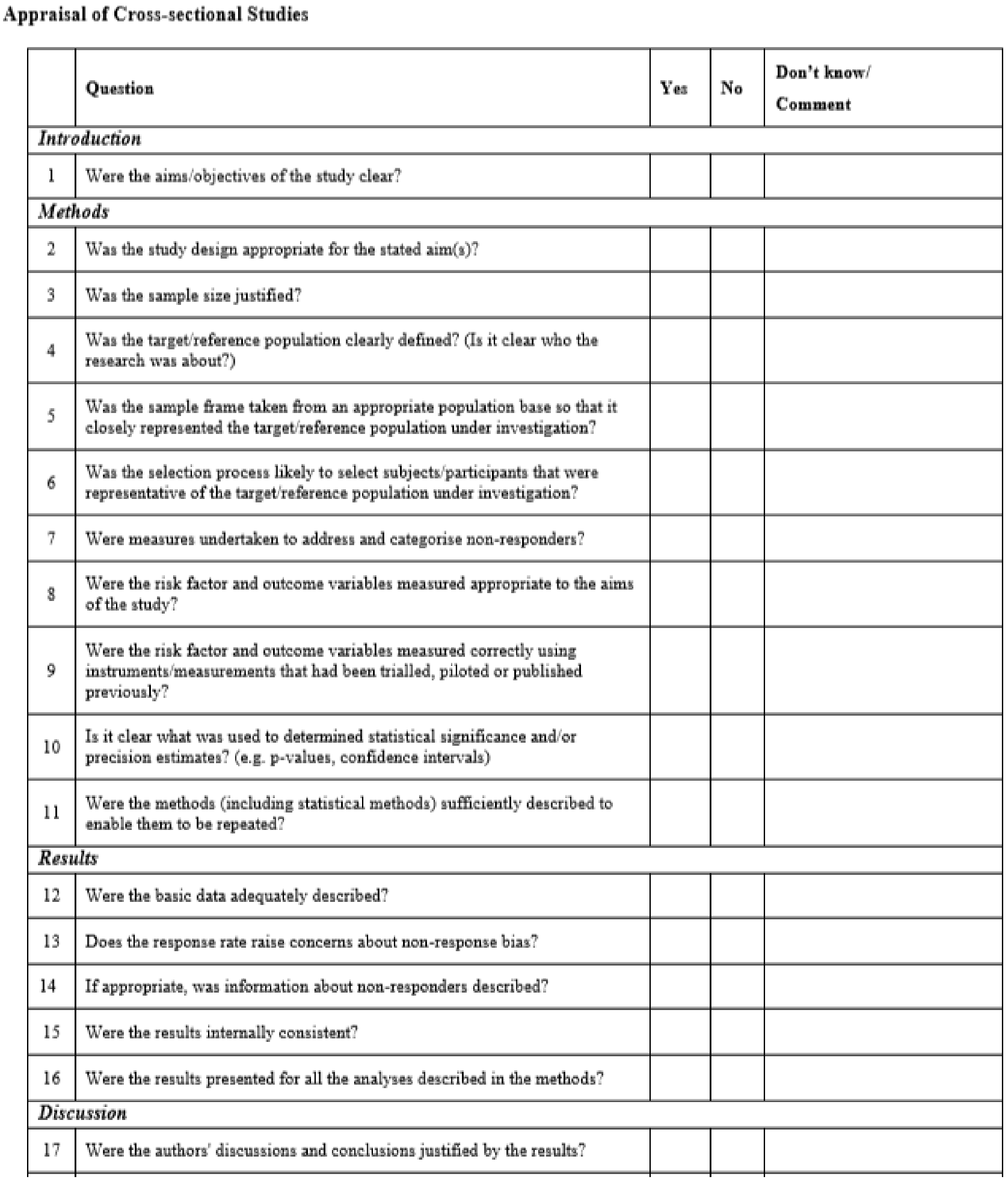
Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- was the trial stopped early
- were patients analysed in the groups to which they were randomised

Comments:

Is it worth continuing?

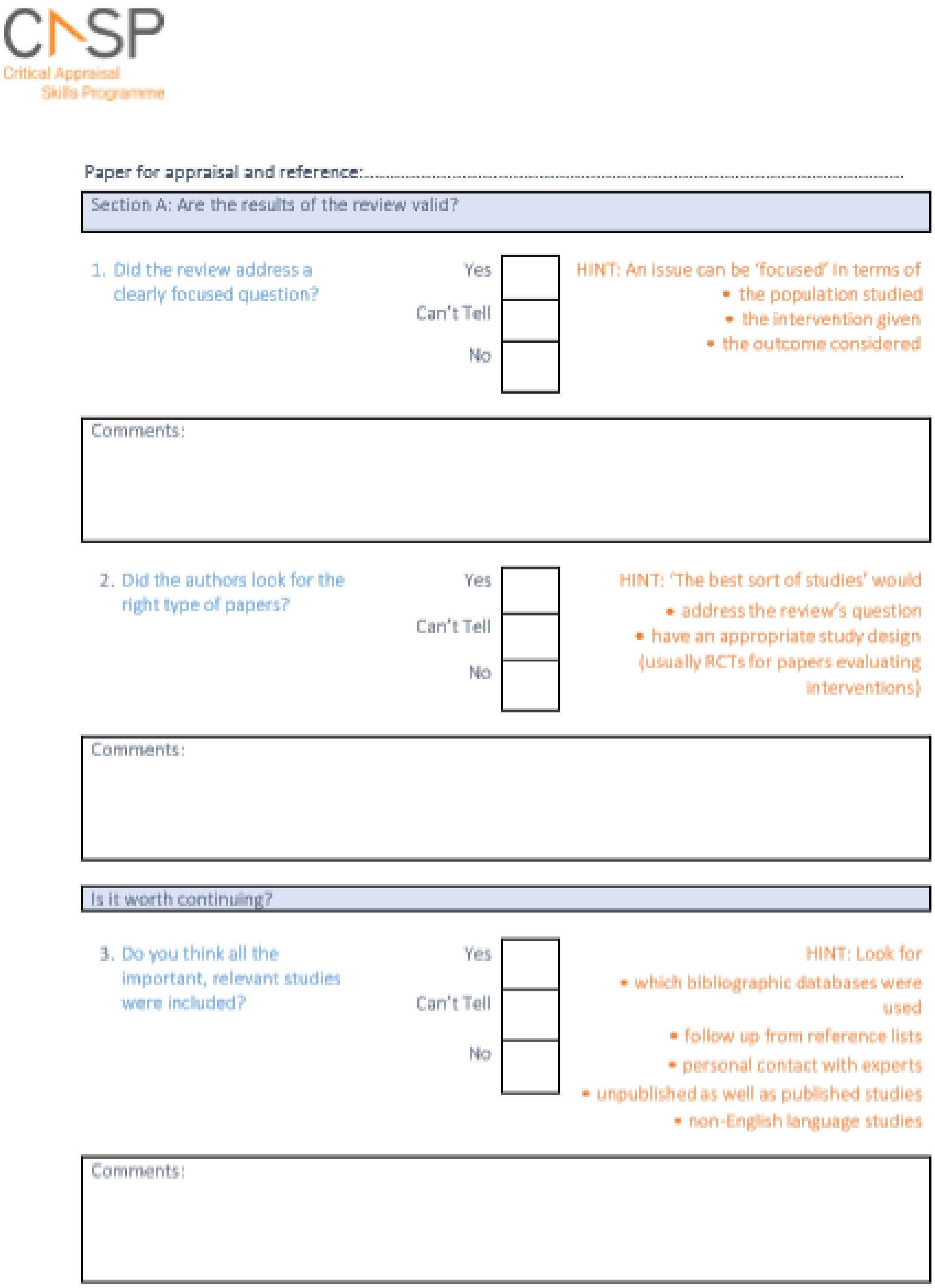
Appendix Five- Appraisal tool for Cross-Sectional Studies (AXIS)



Appraisal of Cross-sectional Studies

	Question	**Yes**	**No**	**Don't know/ Comment**
Introduction				
1	Were the aims/objectives of the study clear?			
Methods				
2	Was the study design appropriate for the stated aim(s)?			
3	Was the sample size justified?			
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7	Were measures undertaken to address and categorise non-responders?			
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results				
12	Were the basic data adequately described?			
13	Does the response rate raise concerns about non-response bias?			
14	If appropriate, was information about non-responders described?			
15	Were the results internally consistent?			
16	Were the results presented for all the analyses described in the methods?			
Discussion				
17	Were the authors' discussions and conclusions justified by the results?			

Appendix Six- CASP Appraisal Tool- Systematic Review



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:…………………………………………………………………………………………

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

Yes ☐
Can't Tell ☐
No ☐

HINT: An issue can be 'focused' In terms of
- the population studied
- the intervention given
- the outcome considered

Comments:

2. Did the authors look for the right type of papers?

Yes ☐
Can't Tell ☐
No ☐

HINT: 'The best sort of studies' would
- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

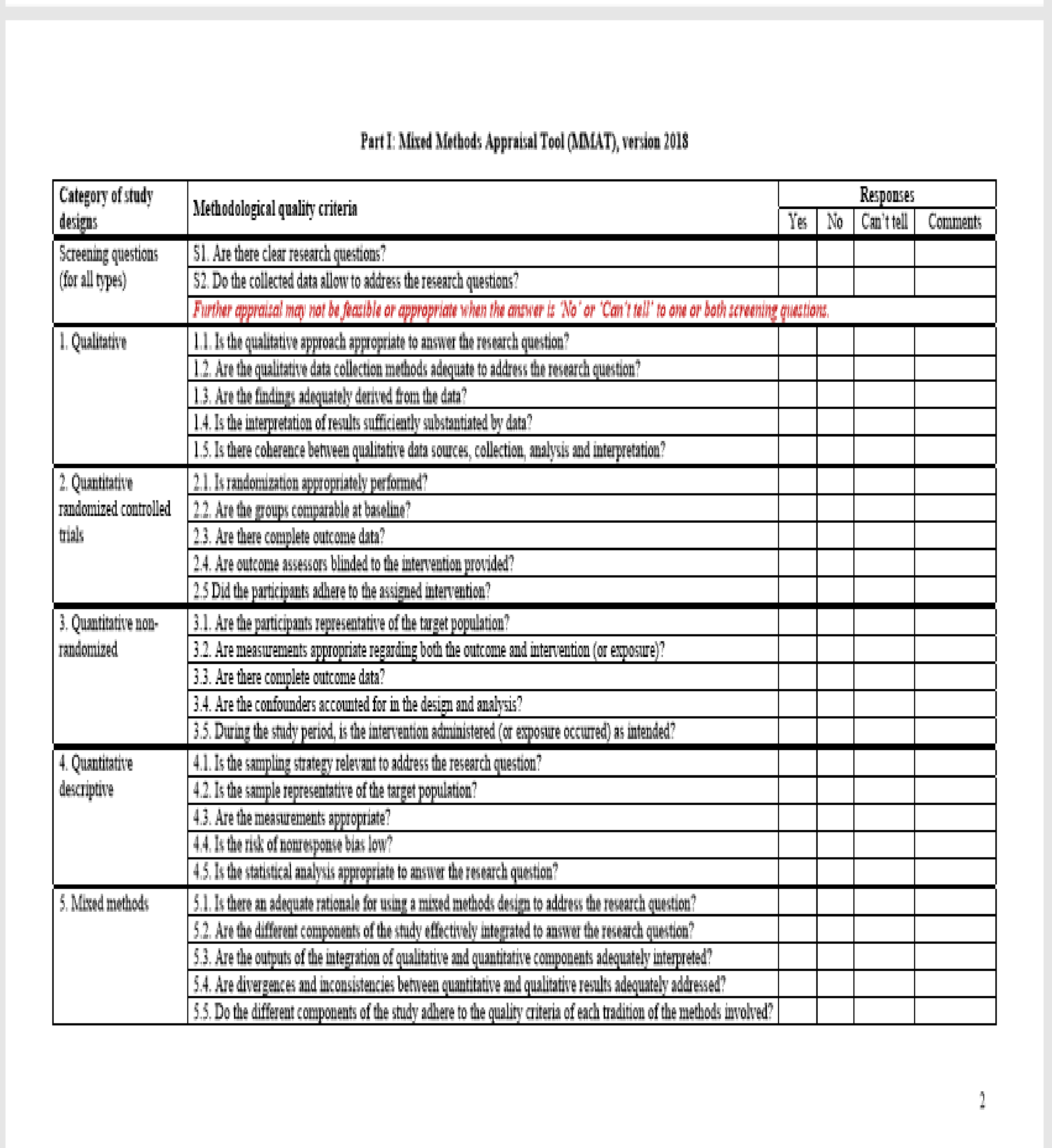
3. Do you think all the important, relevant studies were included?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for
- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments:

Appendix Seven- Mixed Methods Appraisal Tool



Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

2

Appendix Eight- Participant Information Sheet

Participant Information Sheet

My name is Mary Munro and I am a Master of Research student at Robert Gordon University and I invite you to take part in the following study. However, before you decide to do so, I would like to be sure that you understand firstly why I am doing it, and secondly what it would involve on your part should you agree, I am therefore providing you with the following information. Please read it carefully and be sure to ask any questions you might have and I will do my best to explain the project to you and provide you with any further information you may ask for now or later.

Thank you for reading this.

Why have I been invited?

You have been invited as you have been identified as being or have been a support person for an individual with substance misuse issues. This research project aims to gain information on your experiences of being a support person and identify what services you have engaged with and how useful they have been in meeting your needs.

What are the possible benefits of taking part?

By gathering information on your experiences of being a support person this will identify any positive experiences and what is working well for you. However, it may also identify your negative experiences and highlight your preferences for support to help improve service delivery going forward.

What are disadvantages of taking part in the study?

I do not anticipate that there would be any disadvantages to taking part however there is the potential that discussing particular events may evoke feelings of distress or negative emotions. If this does occur I can direct you to relevant services for additional help by providing contact numbers and addresses.

SERP reference number: 18-11

Do I have to take part?

It is up to you to decide whether or not to take part. Participation in this research is entirely voluntary. If you don't wish to take part, you don't have to. If you do not wish to participate, I would appreciate if you could fill out the opt out option available, and I would appreciate if you could tell me why you do not wish to participate. However, this information is entirely voluntary. If you choose not to participate no further contact will be made to you about this study.

This Participant Information Sheet is yours to keep.

If you have any questions about the study, you can contact me or supervisory team using the details provided at the end of this information sheet. You can also discuss your participation with "Involve" http://www.invo.org.uk/ telephone, 023 8059 5628 as an independent source of advice. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I agree to help?

If you agree to participate in this research project a 1:1 interview will be conducted at either a room in the organisation who asked you to take part, or your home setting, wherever is more comfortable for you. The interview should take no longer than one hour, and I will ask you around five leading questions, and at the end of the interview I will ask if there is anything else you would like to address in regard to the study. There should be no harmful effect on you if you choose to participate in the study. The information we gather may not benefit you directly, but we hope that it will be of help in the future to those supporting individuals with substance misuse issues in the Grampian area.

What if something goes wrong?

Any complaints that you have about this study should be addressed to the following individuals:

Professor Catriona Kennedy
Robert Gordon University
Health and Social Care
School of Nursing and Midwifery
Garthdee Road
AB10 7AQ
c.m.kennedy1@rgu.ac.uk

You have the right to raise a formal complaint via the Complaints Officer for NHS Grampian.

NHS Grampian Feedback Service

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Tel: 0345 337 6338

E-mail nhsgrampian.feedback@nhs.net

Will my taking part in this project be kept confidential?

By taking part in the interviews you consent to taking part in this study. Any information obtained in connection with this research project will remain confidential. If you participate in the study you will be assigned a unique study identification (ID) number and your name will not be used in the study. Myself and the two supervisors involved in this project will be the only people who will know which ID number is assigned to you. No identifiable information will be stored and unidentifiable data will stored for 5 years. All study data will be stored safely and securely in a locked filing cabinet in a locked room at Robert Gordon University. Your identity, as well as any information obtained in connection with the study, will remain confidential and will not be shared except as described below. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. Your name will not appear in forms, reports, or publications.

Contact for further information?

Should you wish any further information about the project, please contact:

Mary Munro and/or Professor Catriona Kennedy as detailed above.

Many thanks for taking the time to read and consider your participation in this study

Appendix Nine- Participant opt in/opt out form

Title of the project: A qualitative study on the experiences of psychosocial support available for individuals supporting people with substance use issues in Grampian

Project ID Version and Date: 239868 Version 1 22.03.18

Name of Chief Investigator: Mary Munro – Masters of Research student at Robert Gordon University.

Please tick the appropriate box and initial

	Yes	No
I wish to participate in the study, and consent to providing my details below.	☐	☐

If you do not wish to participate, if you could provide a reason why, the research team would appreciate your feedback, however this is entirely optional.

My reasons why I do not wish to participate are:

………………………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

……………………………………………………………………………………………

SERP reference number: 18-11

My Name	***My Contact Number***	***Best time to contact i.e day/evenings/weekends***

Appendix Ten- Participant Cover Letter

Mary Munro
Robert Gordon University
Health and Social Care Building
School of Nursing and Midwifery
Garthdee Road
AB10 7AQ
m.munro6@rgu.ac.uk

Dear participant,

Thank you for taking the time to consider participating in this research project.
This project aims to gather information on your experiences as a support person of someone with substance misuse issues. You have been asked to participate because you are someone who supports a person with substance use issues.

Included in this pack is a patient information sheet, which tells you about the project and what, taking part means to you. There is also an opt in or opt out form and a consent form to be signed. It is important you understand the information enclosed and can ask any questions you may have.

Once again thank you for your time, and if you decide to participate in this study, I hope that you will benefit from the opportunity to share your experiences which will help us to shape services. If you decide not to participate thank you for taking the time to read this information.

Yours Sincerely

Mary Munro

Appendix Eleven- Ethical Approval Robert Gordon University

Mary Munro

MRes student

Robert Gordon University

19th March 2018

SERP reference number: 18-11

Dear Mary

A qualitative study on the experiences of psychosocial support available for individuals supporting people with substance use issues in Grampian

The School of Nursing and Midwifery Ethics Review panel has now reviewed the above research proposal. Please find details of the outcome and recommended actions below.

* Where the project involves NHS patients, approval through the NRES system must be obtained.

Where the project involves NHS staff, approval through the NHS R&D Office must be obtained.

Members of the School Panel can advise on this process if necessary.

Applicants should provide clear responses to reviewers' comments in the table above. Please include reference to the document on which the change occurs and if possible, a page number.

Please communicate directly with the convenor named below in any process of proposal revision.

Please include your SERP reference number in a footer on all documents related to your study.

Yours sincerely

Panel member 1

Position held: Academic Strategic Lead

Panel member 2

Position held: Lead Research Nurse, NHS Grampian

If you require further information, please contact the Panel Convenor on 01224 263150.

Appendix Twelve- Participant Consent Form

VERSION NUMBER AND DATE: Version 2

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: ***A qualitative study on the experiences of psychosocial support available for individuals supporting people with substance use issues in Grampian.***

Name of Researcher: **Mary Munro**

Please
initial box

1. I confirm that I have read the information sheet dated 22.03.18 Version 1 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, or questioned as to why I have withdrawn. ☐
3. The procedures regarding confidentiality have been clearly explained to me. ☐
4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
5. I understand that interviews may be tape recorded. It has been explained to me that tapes will be stored securely and that I will not be identified by anyone outside the research team. I understand that quotes made by me may be used in any written report, but these will be anonymised. I agree to the use of these quotes. ☐
6. I agree to take part in the above study. ☐

______________________ ______________________ ______________________

Name of Participant Date Signature

______________________ ______________________ ______________________

Name of Person taking consent Date Signature

SERP reference number: 18-11

Appendix Thirteen- Semi Structured Interview Schedule

Participant Interview Topic Guide

REMEMBER PURPOSE OF INTERVIEWS:

1) Explore participants experiences of being a support person and the nature of the support utilised

2) Identify to what extent participants preferences for support are taken into consideration.

Prompts to cover in the standard introduction, prior to interview starting:

Obtain ongoing / process verbal consent

- **Explain they are free to stop the interview at any time, they can request a break at any time and they are under no obligation to continue**
- **Explain that if you write something down, it's because they said something interesting and you want to recall it later**
- **Explain to patients that there are no right or wrong answers**

Once you are assured the participant is comfortable with the above and the interview process, switch on the Dictaphone and start with a standard opening sentence:

I'm interested in your experiences of being a support person of someone with substance use issues, I'm here today to hear about your experiences, and the support that you receive So:

1. Support experience, how long, available- Explore the experiences,

1. Can you tell me a little bit about the person you support and your experience of supporting them?
2. Was there a particular event as a support person that you remember distinctively?
3. What was the biggest challenge you faced at that time?
4. Have there been any positives about being a support person or experiences of support?

WANT TO KNOW - examples as to when a particular event/situation, challenges, positives

5. Are there any services that helped you?
6. In what way have they helped you?
7. Do you have any other support that you find helpful?

WANT TO KNOW- What services, for how long they have accessed, if they haven't accessed services why, how satisfied they are with services they support.

IF they have chosen a service/s – then continue to ask –

You have stated that …. Provide a service, what is it that they provide and do you find this helpful?

WANT TO KNOW – What interventions are being used, does the participant find this helpful?

8. What do you think would be the best service to provide support and what would be the best method?

9. Overall, how do you feel your needs as a support person are met?

WANT TO KNOW- explore examples of preferences being met/not met.

Identify what participants would feel would be the most effective service or intervention to meet their needs.

WANT TO KNOW- What service do they feel would be best to meet their needs.

General Closing:

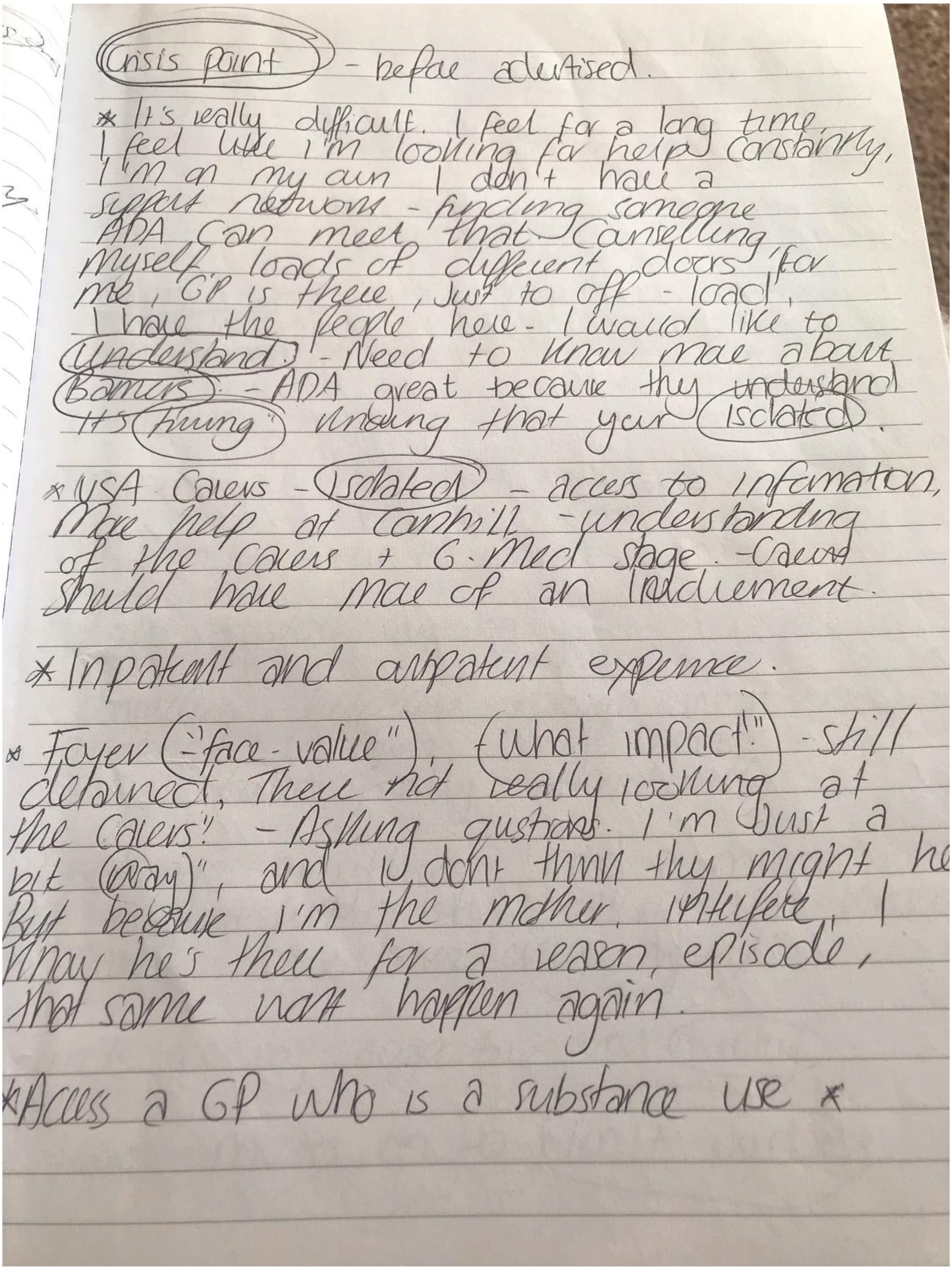
Thank you for sharing your story and experiences with me. It's been really interesting to hear about. Is there anything else about your experiences of being a support person of someone with substance misuse issues, Is there anything you feel we have missed or you would like to tell me? Thank you very much for your time today, I really do appreciate it…

Appendix Fourteen- Data Themes Coding example

Extract	Codes	Category
I have tried one **different route after another trying to find support,** I just feel like I am looking **for help constantly**, so my needs are still not..met…but I might be different…I…I guess what I am trying to say is that I am on my own, I do not have a support network at home, just **trying to find anybody that will understand has been a priority for a while.** (Participant 4, Mother drugs)	Help seeking Different sources Understanding Importance Priority	"Able to identify"
I think that if there was a group out there then yeah…somebody that has the **same things going on**…. I suppose **speaking to other people about it** (participant 1, mother alcohol**)**	Same things Talking to others Similarities Able to relate Understanding	"Going through the same thing"
A positive is **meeting people who understand** and having **the friendship** of people here…**who do….get it** and as much as I have got great friends, **it's difficult to get someone to understand.** They **listen and they say yeah that must be awful but they don't really understand**, but that's not a failing on them**, its just..well the people here get exactly what you are going through** (Mother 4, drugs)	Friendship Getting it Understanding Knowing what you are going through Relatable	"Getting it"
	Friendships	

Yeah, I have **great friends**, it **took me a while to tell them** and I told them incrementally so that was difficult **as it was all so horrible and all so much.** But the friends that I have been great, very supportive. **They don't know what they're talking about of course, nobody can do unless they have been through it themselves** (Participant 5 , mother drugs)	Knowing what you are going through Understanding Relatable Importance Emotional connection Empathy	"Going through the same thing"
Aye, **knowing that you're not alone,** and listening to **other people going through the same thing** to give advice or even just to **understand what it is you're talking about.** (Participant 7, father drugs)	Knowing you are not alone Relatable Understanding	"Going through the same thing"
I definitely would have benefitted from group work or you **know just a group setting really and being able to hear other experiences**, I would have benefitted along with the family to **speak to other people who were going through similar things** (Participant 8, brother drugs)	Listening Experiences Going through the same thing Similarity Relatability	"Getting it"
It's been ***very positive*** *actually the group. The first time I went I was the only one with alcohol problems and all the rest were drug problems,* ***but I discovered out feelings are very similar,*** *we all* ***feel helpless, hopeless, angry have all the same emotions*** *so it is* ***helpful to hear other people's storie****s and in all honesty a lot of* ***them are a lot worse than mine*** (Participant 6 wife alcohol).	Emotional connection Listening Talking Empathy Reflection	"Going through the same thing"

Appendix Fifteen- Extract Reflective diary



Crisis point - before advertised.

* It's really difficult. I feel for a long time, I feel like I'm looking for help constantly, I'm on my own I don't have a support network - finding someone ADA can meet, that counselling myself, loads of different doors 'for me, GP is there, just to off-load', I have the people here - I would like to understand - Need to know more about Barriers - ADA great because they understand It's "tiring" knowing that your isolated.

* USA Carers - Isolated - access to information, More help at Cornhill - understanding of the carers + G. Med stage. - Carers should have more of an involvement.

* Inpatient and outpatient experience.

* Foyer ("face-value"), (what impact") - still detained, There not really looking at the carers" - Asking questions. I'm just a bit (wary)", and I don't think they might he
But because I'm the mother. interfere, I know he's there for a reason, episode, that same won't happen again.

* Access a GP who is a substance use *

Appendix Sixteen- Carers Support Needs Assessment

The Carer Support Needs Assessment Tool (CSNAT)

The Carer Support Needs Assessment Tool (CSNAT) facilitates support for family members and friends (carers) of adults with life-limiting conditions. The research underpinning this tool was informed by carers and practitioners [1,2].

The CSNAT comprises **14 domains** (broad topic areas) in which carers commonly say they require support. Carers may use this tool to indicate further support they need in relation to enabling them to care for someone at home, as well as support for their own health and well-being within their caregiving role.

For use in practice, the CSNAT has been integrated into a **person-centred process of assessment and support** that is practitioner-facilitated but carer led: **'The CSNAT Approach'**.

The CSNAT Approach

The CSNAT Approach is a five-stage person-centred **process of assessment and support** which begins when carers are introduced to the CSNAT [3]. Carers then use the CSNAT to indicate the domains in which they need more support and then prioritise those most important to them at that moment in time.

An assessment conversation then takes place between the carer and practitioner which enables the carer to express their individual support needs. Together, the carer and practitioner agree on what further supportive input would be valuable and create a shared action plan. A shared review of the carers' support needs can then be carried out at another point in time.