

**Investigating the Meaning and Experience of
Quality of Life for Individuals with
Problem Alcohol Use and the Adult Family Members of
Individuals with Problem Alcohol Use**

Eoghan Scott, BSc (Hons)

Dublin City University

School of Nursing, Psychotherapy and Community Health

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Supervisors:

Prof. Anne Matthews, School of Nursing, Psychotherapy and Community Health, DCU

Dr Simon Dunne, School of Psychology, DCU

Dr Malcolm Brady, DCU Business School

Declaration

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Chapter 1: Introduction

The harmful use of alcohol ranks among the top risk factors for disease, disability, and death, causing approximately 3 million deaths a year worldwide and responsible for more than 5% of the global burden of disease (Ritchie & Roser, 2018; WHO, 2014; 2022). Problem alcohol use (PAU) can impact an individual's quality of life (QoL) in many ways, including psychologically (Neupert et al., 2017; APA, 2022), socially (Lintzeris et al., 2016) and physically (Mongan, 2016). PAU can also have adverse effects on the QoL of those close to the individual with PAU, such as affected family members (AFMs) (Copello et al., 2000; Setlalentoa et al., 2010; Anderson, 2011; Alcohol Action Ireland, 2022).

This chapter outlines the background to this study, including the problematic consumption of alcohol throughout the world and Ireland, the issues around PAU, and the impact that PAU can have on the individual and the family. Quality of life in particular will be discussed, focusing on its relationship with PAU. The chapter will concentrate on both the individual with PAU and AFMs (AFMs) of PAU. The chapter will then highlight the impetus of the study and the main aim and objectives and rationale for conducting the research. Lastly, the chapter-by-chapter structure of the thesis will be described.

1.1 Alcohol Consumption Globally

Geographically, alcohol is the leading risk factor for disease in the Western Pacific and America, while in Europe, it is the second most significant risk factor (WHO, 2014). America, Europe, and West Pacific countries take the lead in alcohol consumption, although it has been suggested that up to one-quarter of all levels of alcohol consumption are unreported (WHO, 2016). Geographical differences in alcohol consumption and its ranking

as a risk factor in disease may be explained through socioeconomic differences, cultural differences, or both. Research indicates that people in countries with higher economic wealth tend to consume higher amounts of alcohol and have fewer numbers of alcohol abstainers (WHO, 2014). In contrast, North Africa, Sub Saharan Africa, the Eastern Mediterranean region, the Indian Ocean and South Asia show the highest abstinence rates (WHO, 2014). However, those who consume alcohol in Southeast Asia and Africa consume alcohol at relatively high levels (WHO, 2014).

Numerous factors have been found to relate to a person's risk for substance use problems (including alcohol); age, comorbid substance use, psychiatric comorbidity, family history, gender (Gilbertson, Prather & Nixon, 2008), economic wealth and social/environmental factors (Walton et al., 2003) and self-efficacy (Hasking & Oei, 2004). Some of the major risk factors often cited in the literature are age (Walton et al., 2003; Gilbertson, Prather & Nixon, 2008, WHO, 2016), gender (Walton et al., 2003; Zywiak et al., 2006; Gilbertson, Prather & Nixon, 2008, WHO, 2016) and economic wealth (Walton et al., 2003, WHO, 2016). Humensky (2010) reported that those with parents on higher incomes in the US were statistically more likely to binge drink and use drugs. Government policies on alcohol within different countries may also account for differences in alcohol consumption rates (Leon et al., 1997; WHO, 2014; WHO, 2019).

1.2 Alcohol Consumption in Ireland

Culturally, Ireland has always had a strong association with PAU, and it seems to be a major component of the country's identity (Stivers, 1976; O'Dwyer, 2001; Tilki, 2006). The Health Research Board (HRB) (O'Dwyer et al., 2021) researched alcohol use in Ireland and found

that over half (52.3%) of alcohol users are classified as hazardous drinkers, while two in five drinkers report monthly binge drinking. Alcohol Action Ireland's *Leading Change A Society Free from Alcohol Harm Strategic Plan 2020–2024* (2019) reported that Ireland ranked fifth in the world for binge drinking, with 54 per cent of Irish men and 26 per cent of women classified as heavy episodic or binge drinkers. The HRB also reported that almost two-fifths (39.2%) of drinkers engaged in heavy episodic drinking at least once a month in the previous year before the research, and one-fifth (22.8%) engaged in heavy episodic drinking weekly (O'Dwyer et al., 2021). In another report, the Health Research Board (Health Research Board, 2019) stated that binge drinking among low to moderate risk drinkers accounted for the most alcohol-related harm in the population. They reported that monthly and occasional binge drinkers accounted for 62% of all drinkers in Ireland, consumed 70% of the alcohol, and accounted for 59% of the harms in the population. Previous reports have also revealed 3.8% of the Irish adult population as alcohol dependent (WHO, 2014), while Mongan & Long, (2016) reported that the levels of alcohol dependency in Ireland were rising. Between 2004 to 2008, alcoholic liver disease was the most common cause of death (23.6%). Furthermore, over one-third (36.7%) of deaths for 25 to 34-year olds resulted from liver disease (Lyons et al., 2011). A review commissioned by the Department of Health determined that in 2013, the misuse of alcohol cost the Irish economy €2.35 billion (Hope, 2014). A factor in this may have been the substantial impact alcohol use has on the Irish health services, with alcohol-related discharges increasing by 82% between 1995 and 2013 (Long & Mongan, 2014; Mongan & Long, 2016). The Health Research Board (Mongan & Long, 2016) reported that, in Ireland, alcohol was related to three fatalities daily and was associated with suicidal behaviour. These reports are further supported by research by Malone (2013), who found that substance use was a factor in more than half of completed

suicides, and Griffin et al. (2017), who found that it was a factor in over one-third of self-harm cases.

As outlined above, the implementation of government policy can impact the rate of alcohol consumption. Previously, Ireland has implemented several alcohol-related policies, including raising the legal drinking age to 18, putting restrictions on alcohol advertising, and reducing the accepted legal amount of alcohol allowed in the bloodstream when driving (WHO, 2014). These policies demonstrated some positive impacts. For example, the WHO (2014) reported average alcohol consumption of 13.4 litres between 2003 and 2005, which reduced to 11.4 litres between 2008 and 2010. However, in 2016, Irish per capita alcohol consumption increased by 4.8%, from 10.93 litres in 2015 to 11.46 litres in 2016 (Alcohol Action Ireland, 2018). Furthermore, despite WHO (2014) statistics indicating that the average alcohol consumption levels are seemingly reducing, Davoren et al. (2015; 2016) reported an increase in alcohol consumption in university students, especially women, while Mongan and Long (2016) argued that the levels of alcohol dependency were rising. More recently a report on the impact of COVID-19 on drug and alcohol services by the Irish Government Economic and Evaluation Service (2021) reported that 92 services from a total of 157 reported an increase in alcohol consumption by their service users.

To address problems related to alcohol consumption, such as those mentioned above, the Irish government recently implemented the *Public Health Alcohol Bill* to reduce the rate of consumption to 9.1 litres per capita by 2020 (Department of Health, 2018). However, this might be viewed as still relatively high as the WHO (2018) reported that in 2016 the total alcohol per capita consumption in the world's population was 6.4 litres. Furthermore, noting Ireland's culture and the deep bond developed over time with alcohol, policies may be more challenging to implement effectively.

The above section on the prevalence of alcohol use in Ireland reveals that despite the reduction of consumption levels (Murray, 2017), and the implementation of policies related to alcohol reduction (WHO, 2019), PAU remains an issue in Ireland and Ireland continues to rank high in world consumption levels and binge drinking.

1.3 Terminology

The use of terminology related to problematic alcohol use is varied in the literature. Many terms are associated with problematic alcohol use; for example, addiction, alcohol use disorder, alcohol dependence, binge drinking, and episodic drinking all have specific meanings and applications. Some terms have recently become known as stigmatising terms, such as *alcohol misuse* and *alcohol abuse*. Some believe such terms imply or are associated with negative judgments, punishment and blame (Kelly & Westerhoff, 2010). *Addiction* is a term that is commonly used in the alcohol and drug literature. Addiction is a chronic disorder with biological, psychological, social and environmental factors influencing its development and maintenance (APA, 2022). Addiction is characterized by behaviours that include impaired control over substance use, compulsive use, continued use despite harm, and cravings (American Society of Addiction Medicine (ASAM), 2022; Ries, 2009). *Alcohol Use Disorder* is a principal diagnostic term used in the literature. It can be defined as a problematic pattern of alcohol consumption, characterized by compulsive use of alcohol, impaired control over alcohol intake, and a negative emotional state when not using alcohol (Recovery Research Institute, 2022). *Alcohol dependence* is another term used synonymously with "addiction" but is sometimes also used to distinguish physiological dependence from the syndrome of addiction/substance use disorder (Recovery Research Institute, 2022). *Binge drinking* is defined as drinking four or more alcoholic drinks on one or more occasions for

women or five or more alcoholic drinks on one or more occasions for men (Kanny, Brewer, & Lu, 2013). *Heavy episodic drinking* is defined by the WHO (2018) as consuming at least 60 grams of pure alcohol on at least one occasion in the past 30 days. The term *problem alcohol use* has been increasingly used in the literature (O'Regan et al., 2018; Meredith et al., 2019; Baptist Mohseni et al., 2022). Problem alcohol use was chosen in the current study as an umbrella term to include the varied common definitions and ways of thinking about problematic alcohol use and its related issues. It has been used in this way in the literature before. For instance, Keyes and Hasin (2008) used it in their research to include the terms alcohol dependence and alcohol abuse.

1.4 Impact of Problem Alcohol Use

It has been reported that over 200 health conditions covered by ICD-10 disease and injury codes have alcohol use as a component cause (WHO, 1992; Rehm et al., 2010; Shield et al., 2013). Alcohol use can also contribute to mental health issues such as anxiety disorders (Worden et al., 2015; Karpyak et al., 2016) and is associated with psychological issues such as PTSD/ trauma (Najavits & Johnson, 2014; Killeen, Back, & Brady, 2015), dysthymia (Diaz et al., 2009), emotional regulation (Axelrod et al., 2011) and daily stress (Neupert et al., 2017). Heavy alcohol consumption is even associated with deaths due to homicide, suicide, and automobile accidents (American Psychological Association, 2020; Alcohol Action Ireland, 2021b; WHO, 2022). Problem alcohol use can also directly impact an individual's day-to-day life. For example, alcohol misuse is seen to have a negative impact on access and upkeep of housing (Upshur, Weinreb, & Bharel, 2014) and employment stability (Lintzeris et al., 2016). So evidently, PAU can result in severe adverse outcomes for an individual, not only from a physical aspect but also from a psychological perspective.

Problem alcohol use may not only affect the individual themselves but can also impact others directly and indirectly. For instance, research indicates that alcohol misuse can harm family life (Rotunda, Scherer & Imm, 1995) where family members can suffer a range of adverse effects (Orford et al., 2010; Joolaei et al., 2014). Issues around alcohol-related harm may be particularly important in Ireland. Research on public knowledge, attitudes and behaviour toward alcohol, commissioned by the Health Research Board, has shown that almost three-quarters of the Irish population said that they knew someone who, in their opinion, consumed alcohol excessively. Moreover, 42% of these individuals stated that person to be a member of their immediate family (Ipsos, 2012). Alcohol Action Ireland (2019) reported in their Strategic Plan 2020–2024 that there are likely as many as 400,000 adult children from alcohol-impacted families in Ireland. They also report that a further 200,000 children today are living with and impacted by parental PAU, and 1 in 6 children today are likely living with the traumatic circumstances of a childhood dealing with alcohol-related harms. Some of the lesser noticed impact on children can be known as “hidden harm” (Advisory Council for the Misuse of Drugs, 2003). The impact of PAU on the individual and the family will be reviewed in more detail in the next Chapter in section 2.2.

1.5 Problem Alcohol Use and Quality of Life

The following section will focus on PAU and its association with the QoL of the individual and the family.

1.5.1 The Individual

When investigating PAU and its treatment, Quality of Life (QoL) is an important outcome to consider (Donovan et al., 2005; Laudet, 2011; Luquiens et al., 2012). *Quality of Life* may be defined as the level of need and satisfaction within the physical, psychological, social,

activity, material, and structural domains (Hörnquist, 1982). Another definition of *QoL* is the individual's perception of their position in life and the context of the culture and value systems in which they live and their goals, expectations, standards, and concerns (WHO, 2022b). When examining QoL, it is important to note that there is general QoL, which, as discussed, is a multi-dimensional construct, and health-related QoL (HRQoL), which focuses on a person's perception of how a particular disease may impact their life (Luquiens et al., 2012). While general QoL focuses on overall QoL independent of any health condition, HRQoL is not multi-dimensional as it focuses on symptoms and, therefore, is more limited. Patrick and Erickson (1993) defined HRQoL as the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities influenced by disease, injury, treatment or policy. Definitions of QoL and HRQoL will be discussed further in section 2.1.

Despite these definitions, there is a lack of clarity on how HRQoL applies to PAU. In a systematic review of the literature, Levola et al. (2014) identified social functioning, physical health, mental health, and overall HRQoL as the QoL domains associated with alcohol dependence. On the other hand, Patra et al. (2016) highlighted that physical, psychological, and social QoL domains were significantly lower in alcohol-dependent men compared to control. These are among numerous studies that have examined PAU and QoL, and while there is much research on QoL concerning PAU, there is no one consensus on which domains to include. Further examples of attempts to identify QoL domains for PAU are seen in the following research. Drummond (1990) outlined domains of friends, marriage, children, judicial/legal, employment, finance, physical health, and psychological health. Malet et al. (2006) identified physical functioning, bodily pain, general health, role physical/ limitation, mental health, role emotional/ limitation, vitality, and social functioning. Luquiens

et al. (2015) reported that the important domains concerning alcohol misuse were relationships, activities, looking after self, emotional impact, control, living conditions, and sleep.

The above demonstrates that there is a lack of consensus among researchers concerning the specific domains associated with measuring QoL for individuals with PAU. This issue is further confounded by differences across domains when comorbid diseases are measured alongside PAU. For example, rates of comorbid mental health disorders can be higher in alcohol dependence than in drug dependence (Horton et al., 2011). Furthermore, those with alcohol dependence can exhibit clinical levels of anxiety, major depressive disorder, dysthymia, and dependent personality disorder (Horton et al., 2011).

1.5.2 The Family

Despite the recognised significance of the impact of PAU on AFMs, there is limited, if any, research that focuses explicitly on their QoL. Nonetheless, there is much research available on the impact of PAU on the family that falls under the various domains that can be considered related to QoL, for example, social functioning, physical health, and mental/psychological health. PAU within a family can be related to higher levels of partner physical abuse (Tiwari, Srivastava & Kaushik, 2010; Kishor, Pandit, & Raguram, 2013), higher levels of emotional insecurity (Tiwari, Srivastava & Kaushik, 2010), and adverse effects on coping skills, family role functioning, and marital satisfaction (Kishor, Pandit & Raguram, 2013). Parental PAU is related to higher rates of divorce (Rotunda, Scherer & Imm, 1995; Setlalentoa et al., 2010), while in Ireland, it was previously found that parental alcohol use affected one in ten children "hugely in a negative way" (ISPCC, 2010 p7). Parental PAU can

result in children being exposed to negative role models (Setlalentoa et al., 2010), violence/aggression (Finger et al., 2010; Setlalentoa et al., 2010), and harsher parenting styles (Finger et al., 2010), while it can also have a negative impact on a child's coping strategies (Klostermann et al. 2011), their confidence, and their ability to ask for help (Adamson & Templeton, 2012). PAU in the home can also be associated with conflict (Rotunda, Scherer & Imm, 1995), job performance and legal trouble (Rotunda, Scherer & Imm, 1995), poverty (Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010), social isolation of the family (Setlalentoa et al., 2010), and a lack of friends (Tiwari, Srivastava & Kaushik, 2010). As PAU can bring on disease (Valentine, Bauld & Walter, 2016), and is associated with 3 million deaths per year, 5.3% of all deaths (WHO, 2022), the death of a family member due to PAU can leave a family feeling stigmatised (Valentine, Bauld & Walter, 2016). As a result, a family may lie about the cause of death to avoid being judged by others (Worden, 2018).

1.6 Origins of the Study and Study Rationale

1.6.1 Impetus of the Study

The initial impetus for this study was from a PhD studentship advertised within the School of Nursing & Human Sciences (as it was until 2019) to support the evaluation of a community alcohol treatment programme called Community Alcohol Response and Empowerment (CARE). This programme had previously run as a pilot between the Finglas Addiction Support Team (FAST), Ballymun Youth Action Project (BYAP), and the North Dublin Regional Drug and Alcohol Task Force in Swords. I was selected for the PhD studentship, funded by the HSE Health Service Reform Programme, and commenced in October 2017. Subsequently, following sustained engagement between the research team and the services, the CARE programme did not re-commence due to difficulties recruiting staff, but the

partnership remained and facilitated this study. Therefore, the study's focus moved away from evaluation and instead centred on investigating the meaning and experience of QoL for individuals with PAU and the AFMs of individuals with PAU, which had emerged as important and poorly understood experiences during this engagement.

1.6.2 Study Rationale

One major issue with measuring QoL is the lack of consensus on its definition (Zubaran & Foresti, 2009), which is especially true within PAU treatment (Luquiens et al., 2012). There have been many definitions of QoL (Hörnquist, 1982; Schipper, Clinch, & Olweny, 1996; Wood-Dauphinée & Exner, 2002; WHO, 2014; National Cancer Institute, 2022). Measuring it can be challenging due to the lack of consensus on how many domains should be included within its definition (Testa & Simonson, 1996; Miller & Miller, 2009; Frischknecht, Sabo, & Mann, 2013; Lubman et al., 2016). While there are numerous generic and health-related QoL measures used in PAU, few QoL measures are specific to individuals with PAU.

Furthermore, in an Irish context, the available QoL measures specific to individuals with PAU may fall short for this population. These issues led to the first two objectives of the study: understanding what QoL means to individuals with PAU living in Ireland and exploring how individuals with PAU living in Ireland experience QoL in their daily lives.

There is a scarcity of qualitative research in the literature that focuses on the meaning and experience of QoL for individuals with PAU. QoL research often focuses on quantitative measures and treatment outcomes rather than individual experiences (Laudet, 2011).

However, one qualitative study by Luquiens et al. (2015) centred on developing an alcohol-specific QoL scale by focusing on patients' concerns rather than drinking outcomes and generic health-related QoL instruments. The study conveyed focus groups (n=38) in the UK and France to develop a disease-specific measure for alcohol use disorder; the Alcohol

Quality of Life Scale (AQoLS). Seven domains emerged to determine the basis of the 34-item AQoLS. These seven domains were relationships, activities, looking after self, emotional impact, control, living conditions, and sleep. The authors concluded that further validation was required to confirm the scale's hypothesised dimensional structure and establish its psychometric properties. The current study provides further insight into how individuals with PAU understand and experience QoL, which will hopefully aid in future interventions and services to improve the QoL of these individuals. Furthermore, this study explores the meaning and experience of QoL in an Irish context which is necessary as QoL measures such as the AQoLS (Luquiens et al., 2015) may not be suited to an Irish population.

Notwithstanding the significant impact PAU has on family members, a review of the literature suggests that there is limited research that focuses explicitly on the family members' QoL. This matter is surprising considering that problem alcohol use is related to conflict (Rotunda, Scherer & Imm, 1995), higher rates of divorce (Rotunda, Scherer & Imm, 1995; Setlalentoa et al., 2010), violence/ aggression (Finger et al., 2010; Setlalentoa et al., 2010), higher levels of partner physical abuse (Kishor, Pandit, & Raguram, 2013), higher levels of emotional insecurity (Tiwari, Srivastava & Kaushik, 2010), job performance and legal trouble (Rotunda, Scherer & Imm, 1995), poverty (Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010), social isolation of the family (Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010), negative role models for children (Setlalentoa et al., 2010), harsher parenting styles (Finger et al. 2010), living in poverty conditions (Setlalentoa et al., 2010), and adverse effects on coping skills, family role functioning, and marital satisfaction (Kishor, Pandit & Raguram, 2013). Furthermore, family members of individuals with PAU may feel a profound sense of loss and hurt that can often lead to feelings of deep depression (Anderson, 2011). Given the dearth of research available on family members' QoL, this study aimed to

provide an insight into how family members understand and experience QoL, hopefully benefiting future interventions and services to improve the QoL of family members of those with PAU.

The aims, objectives and rationale for the current study stem from issues identified in this chapter. The above introduction indicated that PAU is a significant problem for the individual and the family, particularly in Ireland, and helped identify two key issues:

- 1) Despite the negative impact PAU has on the QoL of the individual and the family, it is often not addressed as an essential part of treatment. If QoL was developed as a significant patient-reported outcome measure in the treatment of alcohol use and standardised methods for its measurement were developed further, it could help tailor treatment. These developments would potentially improve the clinical state and prognosis of the patient, their QoL, and that of their family. However, before such a measure can be created, there is a need to clearly understand the meaning and experience of QoL for individuals from these groups. Knowing this would then allow such measures to be developed in the future by other researchers.
- 2) There are issues when evaluating changes in QoL brought on by treatment. These issues include the lack of consensus on the definition of QoL (Zubaran & Foresti, 2009), especially within the area of PAU treatment (Luquiens et al., 2012). It would not be enough to assume that definitions of QoL in other areas of health-related research might be the same for research that investigates the QoL of those with PAU and their families. These issues highlight the importance of gaining a deeper understanding of the meaning and experience of QoL for individuals with PAU and AFMs of individuals with PAU. This more in-depth understanding of QoL for both

groups could enhance working definitions of QoL to help evaluate or tailor treatment programs or create effective new treatment programs and objectives.

The above issues form the main aim and rationale for this research, which is to investigate through interviews the meaning and experience of QoL for individuals with PAU and the AFMs of individuals with PAU. Following is a brief section outlining the structure of the thesis.

1.7 Structure of Thesis

The previous section looked at the study's impetus and the main aims and rationale of the research. The following sections are structured: literature review, methodology, findings phase one, findings phase two, discussion phase one, discussion phase two, and conclusion, including new knowledge and significance of findings, the study's strengths, implications, limitations, and finally a reflective section. The next chapter will review the literature concerning the QoL of individuals with PAU and the AFMs of individuals with PAU.

Chapter 2: Literature Review

Chapter One gave the background to this research on QoL concerning PAU. It looked at the worrying consumption rates of alcohol globally and in Ireland and briefly examined the negative impact of PAU on the individual and the family. This highlights how QoL is an influential factor when trying to understand PAU for both the individual and the family. As seen in Chapter One, the main aim of this research is to investigate the meaning and experience of QoL for individuals with PAU and the AFMs of individuals with PAU. This chapter examines the literature available in four main parts. Firstly, part one reviews the literature concerning definitions of QoL, beginning with QoL in general, then QoL concerning health, and finally QoL concerning PAU. It is also necessary to further understand how PAU impacts QoL for individuals with PAU and their families. Part two reviews the literature on QoL and PAU and other literature relevant to understanding the impact of PAU on QoL. Part three firstly examines the potential relevance of QoL to treatment and then examines why QoL is used as a measurement in PAU. Finally, QoL measurement and QoL measurements specific to PAU are reviewed. All of these sections highlight the importance and relevance of QoL and the need to have a greater understanding of it, to be gained within this study.

2.1 Defining QoL

The first part of the current chapter will review the literature to investigate how QoL has previously been defined. In order to define QoL in the context of PAU, the following section will review the definitions of QoL, its origins as a general concept, and its progression to incorporate more specific health-related definitions. Some of the difficulties in defining QoL

will be discussed, and the lack of consensus on definitions will be highlighted. Finally, how QoL is defined in PAU research will be reviewed.

2.1.1 General QoL

The term "Quality of Life" may be traced back to 1948, when the World Health Organisation first stated its current definition of health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (Post, 2014; WHO, 2022c). Since this time, when QoL is defined and operationalised in more general terms, it focuses on overall QoL, independent of any specific health condition.

There have been many definitions of QoL throughout the years, and researchers have found it challenging to agree on how it should be defined. *Quality of Life* was defined by Hörnquist (1982) as the level of need and satisfaction within the physical, psychological, social, activity, material, and structural domains. Whereas Fallowfield (2009, p.1) defined QoL as "a ubiquitous concept that has different philosophical, political and health-related definitions". Examples of global definitions of QoL were also outlined by Abrams (1973), who explained global QoL as the level of satisfaction or dissatisfaction felt by individuals in various aspects of their lives, and Andrews (1974), who related it to how pleasure and satisfaction characterise human existence.

Some different ways to define QoL were suggested by Farquhar (1995), who argued that there were distinct groups of definitions that explained the concept of QoL. These consisted of; global definitions, component definitions, focused definitions or a combination of the above. Farquhar (1995) labelled the most common definitions of the concept of QoL as global definitions as they are all-encompassing. However, these types of definitions restricted

information regarding the possible components of QoL or how it could be operationalised (Farquhar, 1995). These definitions tended to include concepts around satisfaction/dissatisfaction and happiness/unhappiness.

Farquhar (1995) further posited that when the concept of QoL is defined by breaking it down into distinct and essential elements, dimensions, or characteristics, then this may be referred to as a component definition. Additionally, there are component definitions of QoL specific to a specific research topic and those not specific to a research topic. George and Bearon (1981) formed a non-specific component definition that consisted of four underlying elements, two that were objective and two that were subjective and based on the individual's judgment. An example of a research-specific component definition based on research that investigated QoL in nursing homes and long-stay wards for the elderly was reported by Clark and Bowling (1989). They concluded that QoL was not limited to functional ability, mental state, longevity, and activity level. It also encompassed the concepts of freedom, privacy, freedom of choice, emotional wellbeing, respect for the individual, and maintenance of dignity.

More recent definitions of global QoL include one from Michael and Tannock (1998, p 1728), who stated that "a widely accepted definition of quality of life is an individual's own sense of wellbeing as a whole". Wood-Dauphinée & Exner (2002, p. 137) posited that subjective QoL "reflects an individual's overall perception of, and satisfaction with, how things are in their life." The WHO (2022b) define *QoL* as an individual's perception of their position in life, and in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. These four definitions alone

outline a range of terms and phrases that are confusing and open to different interpretations, such as 'perception', 'satisfaction', 'position in life', 'expectations' and 'over time'".

Even with these few definitions mentioned above of QoL, the differences and lack of consensus can be seen. It is because of this that not all scientific papers even attempt to define QoL, and instead of using it as a specific measure, they use it as a general indicator with domains chosen to fit the field of study (Brown, Bowling, & Flynn, 2004). According to Barcaccia et al. (2013), because of the challenge in defining the concept of QoL, many researchers avoid creating a theoretical conceptualisation and instead rely on definitions and theories from other published studies. The difficulties in defining QoL may stem from the multitude of domains and approaches available, as so many factors can be taken into account when attempting to define it. Barcaccia et al. (2013) also suggested that defining QoL had become increasingly complicated because the concept of QoL has spread to so many different areas of research and that the term QoL could be interpreted in many different ways depending on the field of research¹.

As a result of the many different ways to conceptualise QoL, Gasper (2010) suggested that QoL should be understood abstractly. Quality of Life may be an outcome of complex

¹ An example of the diverse application of the construct is research by the Centre of Health Promotion at the University of Toronto. They described the physical factors of QoL as aspects of physical health, personal hygiene, nutrition, exercise, grooming, clothing, and physical appearance (Raphael et al., 1996). These domains were explicitly created with physical health in mind. While these aspects might be very relevant for some individuals, they may be irrelevant, not the most relevant, or not the only relevant domains for others. Physical health may mean something very different to a group of individuals. A high score for some of the domains used by the University of Toronto to describe the physical factors of QoL may apply differently to different individuals. For example, a professional athlete's physical QoL perspective may differ from that of a non-athletic individual. Scores of physical health using this set of domains may not apply in a broader sense of QoL for an individual. For example, an individual may have a good score on their physical health, but negative feelings surrounding career achievements may result in low workplace QoL scores.

interactions between internal and external factors. Internal factors might include personality, life satisfaction, or wellbeing (Evren et al., 2010). External factors might include economic indicators, for example, the availability of goods and services, and social indicators, which would include factors such as crime rates or the quality of the environment (Diener & Suh, 1997; Bullock, 2004).

Quality of Life, as an outcome variable, has been utilised in many different fields of research. A few examples are; education (Ross & Van Willigen, 1997), stress (National Guideline Alliance, 2018), working conditions (Pimenta et al., 2018), housing (McKain, 2019), cardiovascular health (Bergman et al., 2019), and cancer (Svetlakova et al., 2019). Many papers discuss QoL in general terms but fail to give a clear definition of QoL. A 1994 review of papers on QoL by Gill and Feinstein (1994) indicated that, of the 75 articles on QoL they included in their research, few articles defined what QoL meant in their study. Despite drawing attention to the lack of clear definitions in QoL research, little has been done to remedy this. For example, a review by Karimi and Brazier (2016) outlined similar findings to Gill and Feinstein (1994). When reviewing 75 articles on QoL, the authors found that only 15% of the papers defined QoL. The continued avoidance of defining QoL in published literature lends support to Barcaccia et al. (2013) view that "researchers are said not to know what they are talking about when mentioning QoL" (p.185).

These vast research areas and the lack of a clear definition of QoL have left the field of publication open to developing numerous definitions and interpretations. The following section examines the further difficulties in defining Health-Related QoL (HRQoL).

2.1.2 Defining QoL specific to health (HRQoL)

The 1960s saw advances in many areas of medicine (such as oncology) and an associated improvement in many health outcomes. QoL became more relevant in health care as medical treatments for various conditions developed and began to increase life expectancy. Measures of death rates were no longer sufficient when measuring shifts in population health, and there was a need to investigate outcomes beyond morbidity and biological functioning (Karimi & Brazier, 2016). Although general QoL had methodological issues and challenges in forming a consensus on the definition of general QoL, as outlined above, QoL assessment was still regarded as a central part of health research (Muldoon et al., 1998). QoL concepts specific to certain illnesses began to emerge, and this became known as Health-related Quality of Life (HRQoL). It was argued that there was no need for a specific definition to distinguish QoL from HRQoL; that HRQoL is just a measurement of QoL at a particular point in time (Fries, 1990). This view was also held by Guyatt, Feeny, and Patrick, (1993), who stated that many of the concepts and measurements of QoL and HRQoL are interchangeable and refer to the same general idea of health. In contrast, some researchers supported the argument that QoL and HRQoL are different concepts and that HRQoL is a much narrower concept and distinctly different from QoL as it relates only to domains regarding health (Ware, 1991; Moons, Budts & De Geest, 2006).

As with general QoL, HRQoL is challenging to define and there are multiple definitions of HRQoL available. For example, Schipper, Clinch, and Olweny (1996, p.12) defined HRQoL as "subjective and multidimensional, encompassing physical and occupational function, psychological state, social interaction and somatic sensation". Other researchers have described HRQoL as a broad outcome measure designed to measure the physical, emotional, and social dimensions of health (McDowell & Newell, 1996). Bungay et

al., (1996) described HRQoL as the aspects of life that are dominated or significantly influenced by personal health or activities performed to maintain or improve health, including physical, mental, social, and general health perceptions. On the other hand, Testa and Simonson (1996) suggested three principal domains of HRQoL: social, psychological and physical functioning. The Centre for Disease Control and Prevention defined HRQoL as "individuals or groups perceived physical and mental health over time." (2003; 2021), while Fallowfield (2002) suggested four principal domains of HRQOL: physical, psychological/emotional, social and occupational wellbeing.

A paper by Karimi and Brazier (2016) suggested four ways to define HRQoL. The first way was to view HRQoL from two perspectives. The first perspective was how an individual functions in day to day living, for example, whether they can manage to carry out essential activities such as dressing, showering, and getting out to engage in leisure activities. The second perspective was how the individual perceives their wellbeing, in other words, how they feel about their physical and psychological health. The second approach suggested by Karimi and Brazier (2016) to define HRQoL was to measure QoL in an overall way and include illness alongside other domains that may impact QoL. The third way suggested was only to measure aspects of living directly related to their illness, treatment, and level of care. The fourth approach suggested by Karimi and Brazier (2016) was to assign a numerical value to health. For instance, ten might reflect perfect health, and zero equals death.

The difficulties in defining HRQoL continue today (Moons, Budts & De Geest, 2006; Brazier et al., 2014). One possible way of understanding why the difficulties in defining HRQoL in the literature arise is because some definitions fail to distinguish between HRQoL and health or between HRQoL and QoL (Laudet, 2011; Karimi & Brazier, 2016). Despite the

reported difficulties in defining and conceptualizing HRQoL, it continues to be included in health research, and HRQoL continues to be a concept used to measure and evaluate the impact of illness on daily living and as a tool to design, implement and evaluate treatment and services (Muller, Skurtveit & Clausen, 2016). In particular, HRQoL has been studied alongside many different illnesses such as; cancer (Chutikamo, Navicharern, & Lohsiriwat, 2019), opioid use (Rhee & Rosenheck, 2019), HIV (Amara, 2019), neurodevelopmental disorders (Lamsal et al., 2019), and epilepsy (Nawani et al., 2019). Generally, HRQoL can be measured with generic measures, for example; the SF-36 (Brazier et al., 1992), the MOS SF-36 (Ware & Sherbourne, 1992), the SF-12 (Ware, Kosinski, & Keller, 1996), the Nottingham Health Profile (Hunt et al., 1981) or disease-specific measures (e.g. Quality of Life in Epilepsy Scale-10 (Cramer et al., 1996), Diabetes Impact Measurement Scale (Hammon & Aoki, 1992)).

2.1.3 Defining QoL specific to PAU.

As indicated above, many papers discuss QoL but fail to give a clear definition of QoL. Concerning the area of PAU; this practice of omitting QoL definitions in relation to PAU is common (Dawson et al., 2009; Evren, Dalbudak & Evren, 2011; Tran et al., 2014). The literature shows that QoL has been researched in numerous studies that involve individuals with PAU, and there have been different approaches to investigating QoL specific to PAU. For example, some research reports findings on QoL concerning PAU without actually defining QoL. Other research investigates QoL using general QoL and HRQoL definitions and how these definitions applied to PAU, while some researchers attempted to understand QoL by creating a specific definition of QoL in relation to PAU. These issues and the literature pertaining to them is outlined below.

Some examples of research using the concept of QoL to understand PAU but omitting a definition of QoL in their research include a study by Van Dijk, Toet, and Verdurmen, (2004). They examined the relationship between HRQoL and alcohol consumption. The paper did not try to define QoL for PAU. Another example of this type of reporting was seen in a study by Saarni et al. (2007). They measured HRQoL for those with alcohol dependence and other comorbid disorders. While the authors described HRQoL as an "increasingly important outcome measure in healthcare" (Saarni et al., 2007, p.325), they did not try to define HRQoL, despite using QoL as a central concept or measure in their research.

While some papers choose to omit a definition of QoL, another approach evident in the literature is to use general QoL and HRQoL definitions in research and to examine these definitions as they relate to PAU (Gill & Feinstein, 1994; Barcaccia et al., 2013; Karimi & Brazier, 2016). Numerous studies have relied on existing definitions of QoL and HRQoL in their research on PAU (Schipper, Clinch, & Olweny, 1996; Peters, Millward & Foster, 2003). An example of this is in a study by Chen and Storr (2006), where they examined adolescent consumption of alcohol and its impact on HRQoL. Their study defined HRQoL as "a person's perceived physical and mental health over a certain period" (Chen & Storr, 2006, p.1) and used a short, generalized health questionnaire.

Only a modest number of researchers have tried to define QoL concerning PAU. One example is Longabaugh et al. (1994), who defined *QoL* within the area of PAU as "the totality of characteristics of the way of life of an individual or group with particular reference to (1) clinical status with respect to substance use, (2) problems specific to the disorder, and (3) generic health measures focusing on general functioning and health perceptions usually valued regardless of a person's age, or health state." In the research area of PAU, there are

very few studies that define QoL specific to PAU. When looking at the three approaches above, most of the research focuses on using pre-existing definitions of QoL.

The above section reviewed the literature to give an overview of defining QoL. As indicated, the lack of consensus on QoL definitions continues to be difficult (Holmes, 2005; Galloway et al., 2006; Zubaran & Foresti, 2009; Luquiens et al., 2012) and see QoL as a relatively obscure concept (Brown, Bowling & Flynn, 2004). These existing complications, in turn, impact research on QoL and PAU, where it is unclear if existing QoL and HRQoL definitions are adequate, or if definitions of QoL specific to PAU are needed. It could be argued that a definition of QoL relevant to the field of PAU is critical from an ethical standpoint. Decisions on a person's life, for example, access to life-changing or life-saving medications or interventions, can be based upon findings regarding QoL measures (Addington-Hall & Kalra, 2001; Del Cano, 2001). However, as indicated, measures of QoL are often not based on clear working definitions of QoL (Baraccia et al., 2003). Gasper (2010) warned against trying to create a concept of QoL that included as many dimensions as possible and using QoL as an "umbrella term" (p. 359). They suggested carefully choosing those dimensions relevant to the study's main aims and the individuals in the study. Overall, there seems to be growing support for further research and defining and conceptualizing QoL concerning PAU (Zubaran & Foresti, 2009; Luquiens, Reynaud & Aubin, 2011; Luquiens et al., 2012; Frischknecht, Sabo, & Mann, 2013; Levola et al., 2014). The next section reviews the literature on how QoL is measured.

2.1.4 QoL measurements

Chapter Two has highlighted the difficulties in defining and conceptualising QoL. Despite these difficulties and researchers omitting QoL definitions, research still reports that QoL is relevant to understanding PAU. Many quantitative QoL scales commonly used in other areas of research such as cancer (Chutikamo, Navicharearn, & Lohsiriwat, 2019), HIV (Amara, 2019), neurodevelopmental disorders (Lamsal et al. 2019), and epilepsy (Nawani et al., 2019) are often used to understand the impact of PAU, as discussed in part 3 of Chapter Two, but also as a way to evaluate the effectiveness of PAU treatment programs. In order to gain a better understanding of the complexity of measuring QoL, the following paragraphs will review several available measures that researchers in the area of PAU have used. Reviewing QoL measurements highlights the importance of and the need for further qualitative research to unpack the meaning and experience of QoL for individuals with PAU and the AFMs of individuals with PAU. .

As previously discussed, QoL is challenging to define. Generally, it falls under the headings of; general QoL, HRQoL or QoL measures explicitly designed for use in a particular area of research. Research in the area of PAU has used all three types of definitions to create QoL measurements. Table 1.1 shows examples of General QoL measures, HRQoL measures, and QoL measures specific to PAU and highlights the diversity of measurement approached in this area.

Table 1. 1

QoL, HRQoL and PAU-Specific QoL Scales and their Domains

Name	Author/ Year	Type of Scale	Notes	Domains
The Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q)	Endicott et al., 1993	General QoL		Physical health, Feelings, Work, Household, School/ Study, Leisure, Social Activities, General.
WHOQOL-100	WHOQOL Group, 1994	General QoL		Psychological, Physical, Social, and Environmental, Level of Independence, Personal/ Spiritual Beliefs
WHOQOL-BREF	WHOQOL Group, 1998	General QoL		Psychological, Physical, Social, and Environmental
EuroQol (EQ-5D)	EuroQol Group, 1990	HR-QoL		Mobility, Self-care, Usual Activities, Pain/ Discomfort and Anxiety/ Depression
SF36	Ware & Sherbourne, 1992	HR-QoL		Physical functioning (PH), Bodily Pain (BP), Mental Health (MH), Energy/ Vitality (VT), General Health Perception (GH), Role Limitations due to Physical Problems (RP), Role Limitations due to Emotional Problems (RE), and Social Functioning (SF).
WHOQOL-HIV	The World Health Organisation, 2004	HR-QoL		Psychological, Physical, Social, Environmental, Level of Independence, and Spirituality/ Religion

Alcohol Problems Questionnaire (APQ)	Drummond, 1990	Alcohol-specific	Derived from the Troubles with Drinking Questionnaire and the Alcohol Use Inventory	Friends, marriage, children, judicial/legal, employment, finance, physical health, and psychological health.
11-item Alcohol-Related Problems Questionnaire (ARPQ)	Chick, Rund & Gilbert, 1991	Alcohol-specific	Derived from the SF-36	Mental and physical health, legal issues, and housing and employment problems.
Addiction Severity Index (ASI)	McLellan et al., 1992	Alcohol-specific	Other versions of the ASI have been developed, these are the EuropASI and the ASI-Lite (ASL-L-VA).	Physical and mental health, employment/financial problems, judicial/legal problems, interpersonal relationships, psychiatric symptomatology, and substance use (current and lifetime)
9-item Alcohol Index QoL (AIQoL9)	Malet et al., 2006	Alcohol-specific	Derived from the SF-36	Physical Functioning, Bodily Pain, General Health, Role Physical/Limitation, Mental Health, Role Emotional/Limitation, Vitality, Social Functioning
The Alcohol Quality of Life Scale (AQoLS)	Luquiens et al., 2015	Alcohol-specific		Relationships, activities, looking after self, emotional impact, control, living conditions, and sleep

There are numerous ways to measure general QoL over many different domains.

There are some overlaps and agreements; for example, psychological health is a noteworthy domain within QoL. However, terms used to label each of the domains differ and several domains are not found repeated through each of the measures. Just as was seen when defining general QoL, there appears to be no consensus on which domains should be included for

measuring QoL among individuals with PAU. The WHOQOL-100 (WHOQOL Group, 1994) includes six broad domains to measure general QoL; Physical health, psychological health, level of independence, social relations, environment and personal/spiritual beliefs (De Vries & Van Heck, 1997). Miller and Miller (2009) argued that QoL could have at least eight sub-domains of subjective well-being alone, including, for example, creativity, self-esteem and a sense of meaning or purpose in life. QoL can also be measured through the domains of 'overall QoL', 'physical aspects', 'psychological aspects', 'social life', and 'everyday life' (Frischknecht, Sabo, & Mann, 2013) or the four domains (psychological, physical, social, and environmental) of the World Health Organisation QoL Brief Scale (WHOQoL- BREF) (WHOQOL Group, 1998). With the availability of so many measurements, and a continually growing body of research using general QoL scales, choosing which one is best to use is challenging.

There are also recognised issues with current general QoL scales. For instance, research by Gabriel and Bowling (2004) reported on QoL for senior citizens, stating that a feeling of safety, retaining independence and control over life was relevant to this group. They argued that many domains identified by a particular cohort might be specific to them but not relevant to another cohort. Other research agreed with the difficulties in generalising findings to specific cohorts. For example, Luquiens et al. (2012) stated that general QoL instruments measure overall well-being, i.e. the satisfaction of needs and desires familiar to most individuals but not 'all'. This view suggests that every individual has a distinct understanding and meaning of what QoL is to them and that research should be detailed and explicit when operationalising the concept of QoL (Post, 2014).

Numerous measurements are also available to measure HRQoL, which is relevant to health care evaluations (Tarlov et al., 1989; Epstein & Sherwood, 1996). As mentioned above, with general QoL and the multitude of domains available, HRQoL domains have some similarities and some differences (see Table 1.1). For example, Drummond (1990) determined HRQoL domains to be; friends, marriage, children, judicial/legal, employment, finance, physical health, and psychological health. On the other hand, Malet et al. (2006) classified HRQoL domains as; physical functioning, bodily pain, general health, role physical/ limitation, mental health, role emotional/ limitation, vitality, and social functioning. Luquiens et al. (2012) then proposed four domains of HRQoL. These were; physical state (i.e. physical abilities), physical well being (i.e. pain), psychological state (i.e. anxiety and depression), and social relationships (i.e. family, friends, work). In a systematic review of the literature, Levola et al. (2014) distinguished social functioning, physical health, mental health, and overall HRQoL as the primary QoL domains associated with alcohol dependence, while Luquiens et al. (2015) described the relevant domains regarding alcohol misuse as relationships, activities, looking after self, emotional impact, control, living conditions, and sleep.

HRQoL scales must also be viewed cautiously as they fall prey to the same methodological difficulties as general QoL scales. Lin, Lin, and Fan (2013) reported some of the main methodological issues with HRQoL research: objectivity/ subjectivity, generic/ specific, reliability, validity, and criteria for selecting HRQoL. Often the nature of HRQoL scales is to use them as a measure for a specific illness, but the spectrum of illness and its relation to the individual includes many individual factors such as; symptoms, outlook, personal beliefs and support (Testa & Simonson, 1996). Strada et al. (2017) argued that HRQoL measures are specific to a particular disease, whereas general QoL measures

correspond to many populations. Table 1.1 gives examples of general QoL and HRQoL measures. Despite some of the methodological issues outlined above, researchers in PAU continue to use both general QoL scales and HRQoL scales in many areas of research. The following paragraphs examine the use of general QoL and HRQoL measures in evaluating PAU treatment.

Some research has used general QoL scales when investigating the impact of problem substance use (Ginieri-Coccossis et al., 2007; Srivastava & Bhatia, 2013). An example of general QoL scales in PAU is illustrated in a study by Srivastava and Bhatia (2013). They investigated QoL changes over three months of 56 alcohol-dependent patients aged 18-45 years. They compared it to the QoL of 150 healthy controls using the 26-item WHOQoL BREF questionnaire (WHOQOL Group, 1998) at baseline and three-month follow-up. The detoxification program consisted of medication for alcohol withdrawal and medical or psychiatric comorbidities, vitamins, and psychosocial interventions, including motivational interviewing, psychoeducation groups and counselling sessions for both patients and family members. Caregivers, usually family members, were involved in the treatment process. Initial baseline assessment of QoL reported significantly lower scores in physical, psychological, social, and environmental domains of QoL for those with alcohol dependence compared to controls. At the same time, results revealed significant improvements in the QoL of patients over three months' abstinence from alcohol. Furthermore, regular follow up with the family members in an outpatient setting helped maintain abstinence and further improve QoL.

HRQoL scales are also often used in PAU research, where PAU is treated as a chronic illness. For example, the French version of the Medical Outcome Study SF-36 was used on admission and at discharge to measure the QoL of 414 alcohol-dependent patients from a 3-

week inpatient withdrawal program (Lahmek et al., 2009). The program consisted of medical treatment for alcohol withdrawal, psychiatric and somatic comorbidities, and standardised psychosocial treatment. Overall, the SF-36 scores were significantly lower on admission than at discharge, where scores for the eight scale dimensions were similar to those for the general French population.

A further example of HRQoL scales in PAU research is the study by Daeppen et al. (2014). After the initial baseline assessment, they examined HR-QoL changes in 160 adults with alcohol dependence over two years. QoL was measured at baseline and quarterly using The Medical Outcomes Study 36-Item Short-Form Survey (MOS-SF-36). The treatment program comprised a routine practice setting where patients were offered standard care by physicians, nurses, and psychologists through motivational interviews, relapse prevention measures, and medication based on the patients' chosen treatment objectives. Outpatients had the opportunity to attend weekly individual or group sessions, while inpatients took part in a structured 3-week inpatient program consisting of a withdrawal program, medical treatment, and psychotherapy. Results revealed improvements in the mental dimension of QoL following treatment initiation, and these improvements were maintained for the subsequent 24 months.

The above are just some examples of the use of pre-existing or non-alcohol-specific QoL scales in PAU research. Some would argue that using such pre-existing scales is not sufficient, and scales specific to QoL in those with PAU should be created for use in PAU specific research (McLellan et al., 1996; Ugochukwu et al., 2013). However, alongside general QoL scales, health-related QoL scales and more alcohol-specific QoL scales, there are also individualised measures of QoL. Individualised measures of QoL address the

person's specific concerns in contrast to external, potentially less individually relevant standards that would consist of fixed, predetermined questions (Gallagher & Desmond, 2007). Measures such as these allow respondents to choose and prioritise important aspects of their lives, therefore acknowledging QoL's relative and variable nature across individuals (Gallagher & Desmond, 2007). Some examples of individualised measures of QoL are the Patient Generated Index (PGI; Ruta et al., 1994) and its modified version, the Modified Patient Generated Index (MPGI; Dempster & Donnelly (2000), the Schedule for the Evaluation of Individual Quality of Life (SEIQoL; McGee, 1991; O'Boyle et al., 1992) and its briefer direct weighting procedure (Hickey et al., 1996), and the Subjective Domains of QoL Measure (SDQLM; Amir, Bar-On, & Penso, 1996).

Taking the PGI (Ruta et al., 1994) as an example of such an individualised measure, this scale focuses on the impact of a disease on an individual's QoL and uses semi-structured interviews to collect data and allow the individual to freely choose and prioritise important areas in their life. A rating and weighting procedure then follows this. Similarly to the PGI, the SEIQoL (McGee, 1991; O'Boyle et al., 1992) also uses semi-structured interviews to collect data and allow the individual to freely choose and prioritise important areas in their life and is followed by a rating and weighting procedure. However, it focuses on QoL in general rather than the impact of a disease on an individual's QoL. Another example of individualised measures of QoL is the Subjective Domains of QoL Measure (SDQLM) (Amir, Bar-On, & Penso, 1996). This measure also allows individuals to specify areas of importance in their life, rate these areas, and rank the importance of each area. These methods of highlighting QoL domains that are relevant to the individual, and emphasising what priority is given to them, can improve a particular measure's responsiveness to change because what is being measured is important in the life of the individual (Carr & Higginson,

2001; Gallagher & Desmond, 2007). Scales specific to QoL for those with PAU will be reviewed in the next section.

2.1.5 QoL measurements specific to PAU

As previous paragraphs indicated, general QoL and HRQoL have various measurements available that have been utilised in PAU treatment evaluation (McLellan et al. 1996).

However, these measurements are not without their difficulties, and some researchers argue that using existing general QoL and HRQoL measurements within research on PAU is not always considered best practice (Ugochukwu et al., 2013; Malet et al., 2006). Even so, many of the scales of QoL specific to PAU have taken existing QoL and HRQoL measurements and adapted them for use with PAU (Ugochukwu et al., 2013). Some researchers have argued that QoL measures specific to PAU are needed (Ugochukwu et al., 2013; Luquiens et al., 2015). There has been some movement in creating QoL measurements specific to PAU, as shown in Table 1.1. However, the move to create QoL scales specific to PAU is still in the early stages. Ugochukwu et al. (2013) reviewed 50 studies over 40 years of research (1971 – 2011) on QoL and PAU. The review revealed that 12 measures were adopted to investigate QoL in alcohol abuse and dependence. These 12 measures could be grouped into two sub-categories: global measures (used in various disorders) and alcohol-specific measures. The authors found that, while many of the general QoL measurements had been created and tested for reliability and validity, measurements specific to QoL and PAU have yet to be validated. They further argued that as PAU can profoundly impact individuals and their families, extensive measures should be taken to quantify changes in QoL as part of treatment evaluation. They noted that the number of measurement instruments available is minimal and not as widely tested for reliability and validity as generic measures and measures for other

areas of health research (Ugochukwu et al., 2013). The following paragraphs review QoL measurements specific to PAU.

One measure that investigates QoL issues for those with alcohol and drug abuse problems is the Addiction Severity Index (ASI) (McLellan et al., 1992), used extensively in alcohol-related QoL evaluations. The ASI is a structured interview that lasts one hour and investigates seven QoL domains. These domains are; physical and mental health, employment/ financial problems, judicial/ legal problems, interpersonal relationships, psychiatric symptoms, and current and lifetime substance use. The ASI aims to reveal particular areas of distress so that treatment can focus on the appropriate domains of low functioning. It also evaluates the family history of alcohol and drug abuse and psychiatric disorders. The reliability and validity of the ASI have previously been established; however, some limitations include the length of time it takes to conduct the interview, the lack of quantification of substance use, and the complex evaluation of family and social relationships. Other versions of the ASI have been developed to reduce these limitations. Examples are the EuropASI (Kokkevi & Hartgers, 1995) and the ASI-Lite (ASL-L-VA) (McLellan et al., 1992).

The SF – 36 (Brazier et al., 1992) has been adapted to create other scales for use in PAU research. The 36-item self-administered questionnaire is considered reliable and valid (Brazier et al., 1992; Volk et al., 1997). It measures health on eight multi-item dimensions: physical functioning, social functioning, physical problems, emotional problems, mental health, vitality, pain, and general health perception. Volk et al. (1997) concluded that the SF-36 was a valid and sensitive scale for alcohol dependence, patterns of consumption, and evaluation of treatment effect on QoL. An example of an alcohol-specific measure derived

from the SF-36 was the 11-item Alcohol-Related Problems Questionnaire (ARPQ) (Chick, Rund & Gilbert, 1991). Patience et al. (1997) used this scale to investigate QoL in the domains of mental and physical health, legal issues, and housing and employment problems. The authors revealed that the ARPQ scores closely correlated with SF-36 scores across all domains. However, they argued that it was more accessible and convenient to use while yielding more immediate results.

The 9-item Alcohol Index QoL (AlQoL9), developed by Malet et al. (2006), was also adapted from the SF-36. This scale was found to be highly specific and sensitive, while it revealed high internal consistency and reliability. It was also reported to be highly representative of the QoL domains most influenced by alcohol dependence (Malet et al., 2006). Zubaran and Foresti (2009) reviewed QoL in the broader context of substance use and reported that they discovered only one scale validated explicitly for alcohol-dependent; the ALQoL-9. However, not all of the literature supports the SF-36 and the subsequent PAU measures developed from it. For instance, Daeppen et al. (1998) reported that the physical functioning subscale of the SF-36 varied only slightly from the healthy population in comparison to the mental subscales. This comparison revealed that individuals might perceive their problems as more psychological rather than physical; this could impact results as both physical and psychological factors seem to be impacted by PAU. Luquiens et al. (2015) argued that although the AlQoL9 was the only disease-specific HRQoL instrument for alcohol dependence, it lacked patient input because it originated from an existing HRQoL measurement.

Another alcohol-specific scale is the Alcohol Problems Questionnaire (APQ). This scale, developed by Drummond (1990), contains 44-items within eight domains. These

domains are; friends, marriage, children, judicial/legal, employment, finance, physical health, and psychological health. The scale is derived from the Troubles with Drinking Questionnaire and the Alcohol Use Inventory; however, while these scales measure alcohol dependence, the APQ scale does not, as it focuses solely on alcohol-related QoL deficiencies. There are reported limitations to the APQ. For example, Ugochukwu et al. (2013) stated that the severity of alcohol-related QoL deficiencies could not be investigated as the items in the scale were dichotomous. Furthermore, they reported that this scale's reliability and internal and external validity as a measure of alcohol-related QoL needed further investigation. One qualitative study by Luquiens et al. (2015) centred on developing an alcohol-specific QoL scale by focusing on patients' concerns rather than just on drinking outcomes and generic health-related QoL instruments. The study comprised focus groups with 38 individuals living in the UK and France, and data collected from these focus groups was used to develop a disease-specific measure for alcohol use disorder; the Alcohol Quality of Life Scale (AQoLS).

2.2 Understanding the impact of PAU

Some of the primary disease and injury categories causally linked to alcohol, in particular, long-term heavy alcohol use, are neuropsychiatric conditions (for example, epilepsy, anxiety or depressive disorders), brain damage, gastrointestinal diseases (for example, liver cirrhosis), cancers, cardiovascular problems, foetal alcohol syndrome, and preterm birth complications (Karpyak et al., 2016; WHO, 2019). Short-term effects of heavy alcohol use are hangovers, memory loss, and blackouts (Howse et al., 2018). In Ireland, we can see similar evidence of the impact of PAU on the individual in terms of their physical, psychological and everyday living perspectives. According to Hope et al., (2005), almost a quarter of those injuries attending accident and emergency services were alcohol-related; of

these incidences, over three quarters were intoxicated. Daly (2006) reported that 14% of admissions to psychiatric hospitals were for alcohol disorders. A national study in Ireland indicated that alcohol was the most frequently used drug reported in intentional overdoses (Daly et al., 2018). For day to day living from an Irish perspective, the long-term impacts of PAU can result in problems in family life, education, employment, crime (Health Research Board, 2011) and homelessness (Glynn, 2016).

Although "the association between alcohol consumption and HRQoL is not well understood" (Volk et al., 1997, p. 899); an association between PAU and QoL is evident, and there is a growing body of literature to support the link between QoL and PAU (Malet et al. 2006; Laudet, 2011; Luquiens et al., 2012). PAU impacts the QoL of those with pre-existing illnesses; for example, Schuckit (2009) reported that alcohol use disorders and alcohol abuse could make psychiatric disorders worse. The physical damage caused by PAU, such as diabetes, cirrhosis of the liver and increased pressure on the heart, is seen to also negatively impact an individual's QoL (Malet et al., 2006; Patra et al., 2016). It is not just the physical consequences of PAU that impact QoL; there are various other factors to consider, such as the individual with PAU and their overall mental health, social functioning, and relationships with family members, to name just a few (Drummond, 1990; Malet et al., 2006; Luquiens et al., 2015). In general, PAU causes suffering, and this, in turn, reduces the individual's QoL (WHO, 2019). The more areas of life that are negatively impacted by PAU, the higher the potential for lowering QoL.

PAU is broad in that it impacts not only the individual but can also disrupt family life (Rotunda, Scherer & Imm, 1995). A 1991 study suggested that over 43% of individuals living in the USA had a family member with PAU (Schoenborn, 1991), while Copello et al. (2000)

asserted that an individual with PAU will adversely affect at least two family members. At times there can be severe consequences for a family's safety and wellbeing due to PAU (Butler & Bauld, 2005; Oreo & Ozgul, 2007; Yuen & Toumbourou, 2008; Hope, 2014) and caring for a family member with a substance use problem can be a heavy burden for a family or even those around them (Jiang et al., 2015). An individual's PAU can impact each family member differently (Tiwari, Srivastava & Kaushik, 2010). Family members who are most affected by someone's PAU are spouses and children (Tiwari, Srivastava & Kaushik, 2010). Anderson (2011) described living with a partner with PAU as "regular, ongoing and intense" stress that leads to feelings of worry and exhaustion. However, the impact of PAU on family members can be unique to each (Tiwari, Srivastava & Kaushik, 2010). There is a range of adverse effects on the family due to PAU (Orford et al., 2010; Joolae et al., 2014). A review from 2000 reported that almost 10 million children were living in a family with at least one member with PAU (Grant, 2000). This report is worrying, considering children can be significantly affected psychologically and emotionally by PAU in the family and by parental PAU (Grant, 2000; Dube et al., 2002; Gruber & Taylor, 2006; ISPC, 2010). PAU is associated with harsher parenting styles (Finger et al., 2010), and it is also associated with children witnessing violence (Finger et al., 2010; Setlalentoa et al., 2010). PAU in the family can negatively impact a child's confidence and ability to ask for help (Adamson & Templeton, 2012). Physically, if a mother has PAU, it can cause foetal alcohol syndrome (Christoffersen & Soothill, 2003). The risks of a child being born brain-damaged or with lower length, birth weight, or visual defects can also increase due to PAU (Rydellius, 1997; Christoffersen & Soothill, 2003). Up to 72% of the Irish population is thought to know someone that has PAU, and 42% of these are family members of the individual with PAU (Ipsos, 2012).

As the above paragraphs outline, PAU can have a profound negative impact on the individual and their family (Reanet, Martin & Speight, 2008; Karimi & Brazier, 2016). There are, however, some issues with research that may prevent getting the most comprehensive review on the impact of PAU on QoL. For example, some complications arise in understanding the impact PAU has on QoL, namely, 1) the lack of consensus on defining QoL and 2) research that indirectly focuses on domains of QoL without using the terms QoL or HRQoL. The first complication is that the lack of consensus on QoL definitions results in academic papers using a variety of definitions. Some of these are general QoL (WHO, 2022), some are HRQoL (Karimi & Brazier, 2016; Centre for Disease Control and Prevention, 2003; 2021), and some define QoL specific to PAU (Longabaugh et al., 1994). As a result, the areas of QoL, or domains as they are often referred to, impacted by PAU are also varied and numerous. For example, Malet et al. (2006) reported physical functioning, bodily pain, general health, role physical/ limitation, mental health, role emotional/ limitation, vitality, and social functioning as domains of QoL impacted by PAU. Levola et al. (2014) stated that PAU impacts QoL under the following domains; functioning, physical health, mental health, and overall HRQoL. Luquiens et al. (2015) outlined QoL domains as relationships, activities, looking after self, emotional impact, control, living conditions, and sleep. In a study by Patra et al. (2016), the QoL domains outlined were; physical, psychological, and social. These are but a few examples of domains of QoL impacted by PAU and illustrate the difficulties in reaching a consensus on what QoL domains should be reviewed when attempting to understand the impact of PAU. Furthermore, as discussed earlier in Chapter Two, some research articles do not define QoL or only mention it as a general concept. When reviewing the impact of PAU, some articles may not even mention QoL as a term but examine areas that could be included under QoL (e.g. Daly, 2006; Gruber & Taylor, 2006). The current literature review included research on the impact of PAU on individuals and their families,

regardless of directly explaining the impact on QoL, when necessary; especially as the research on the direct impact of PAU on the QoL of family members is limited (Copello, Velleman, & Templeton, 2005).

Considering the above difficulties, a review of the literature on QoL, its definition and how it is measured (reviewed in Chapter Two) produced many possible domains or dimensions under which QoL can be conceptualised. Table 1.1 (page 36) gives an overview of available domains of QoL and Figure 1.1 took the information on domains from each table and grouped them into four general categories: physical, psychological, environmental/social, and other. Figure 1.1 also gives a brief list of possible domains included under each category taken from Table 1.1. The following section will review the literature under these four domains. Even though the papers in the following paragraphs are not always directly related to QoL, through triangulation of the information available on PAU and QoL, they help build a more comprehensive overview of the construct.

Figure 1. 1

Qol Domains Organized Under Four Main Categories with Examples from Table 1.1



2.2.1 Physical impact

2.2.1.1 Physical impact on the individual.

PAU has been reported to negatively impact an individual's physical health in many different ways, for example; sleep apnoea (Carole et al., 1981; Strohl & Redline, 1996; Schuckit, 2009), heart problems (Fuchs et al. 1995; Thun et al., 1997; Hallgren, Högberg & Andréasson, 2009), foetal alcohol syndrome (Poskitt, 1984; Schuckit, 2009; Guerri, Bazinet, & Riley, 2009), liver cirrhosis (Schuppan & Afdhal, 2008; Tsochatzis, Bosch, & Burroughs, 2014), cancer (International Agency for Research on Cancer, 1988; Pöschl & Seitz, 2004; Boffetta & Hashibe, 2006; Dguzeh et al., 2018), diabetes (Hallgren, Högberg & Andréasson, 2009; Babor et al., 2012; Dguzeh et al., 2018), metabolic syndrome (Baik & Shin, 2008; Hallgren, Högberg & Andréasson, 2009), less physical fitness (Hallgren, Högberg & Andréasson, 2009), and brain damage and brain injuries (Harper, 2009; Zahr, Kaufman, & Harper, 2011). PAU may also cause physical impairment and can increase the risk of violence and injury (Jayaraj et al., 2012). PAU is also associated with HIV, a common topic in QoL research. High levels of PAU have been reported to adversely impact the QoL of individuals with HIV (Byrne & Petry, 2013), while PAU is shown to adversely impact outcomes concerning HIV treatment (Van Dyk, 2012; Graham et al., 2016; Madhombiro et al., 2017). In Ireland, over one-quarter of injuries in A&E are related to alcohol (Hope et al., 2005; Alcohol Action Ireland, 2021b). Alcoholic liver disease accounted for almost four-fifths of all alcohol-related chronic diseases in Ireland in 2013 (Mongan, 2016), while alcohol is associated with 25% of traumatic brain injuries (Alcohol Action Ireland, 2021b) and 10% of breast cancer cases (Health Research Board, 2016).

Although the above factors are not explicitly focused on QoL, if we look closely at how PAU can impact an individual's physical health, we may also see the negative consequences PAU can have on an individual's QoL. For example, research shows how PAU is associated with cardio health problems (Fuchs et al., 1995; Thun et al., 1997; Hallgren, Högberg & Andréasson, 2009), while at the same time research has shown that cardio health problems can adversely affect QoL (Juenger et al., 2002; Uzark et al., 2008). The same can be seen in other physical areas impacted by PAU. For example, research has shown that liver disease (Marchesini et al., 2001; Younossi et al., 2001) and diabetes (Meijer et al., 2001), both often worsened by PAU, are associated with lower levels of QoL.

2.2.1.2 Physical Impact on the Family. Family members of those with PAU are also impacted in many different ways that can be classed under the physical domain of QoL (Finger et al., 2010; Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010; Kishor, Pandit, & Raguram, 2013). PAU is associated with verbal and physical intimidation of family members (Jackson & Mannix, 2003), an increased risk of violence towards family members (Morrill et al., 2001), and more severe injuries within these instances of violence (Reider, 1988). Domestic violence and higher levels of partner physical abuse are associated with PAU (Tiwari, Srivastava & Kaushik, 2010; Kishor, Pandit, & Raguram, 2013). Alsaker et al. (2006) stated that being a victim of domestic abuse has long term adverse physical consequences, such as violent physical and sexual attacks. Children of those with PAU are at risk of being victims of direct physical violence and are more at risk of witnessing violence due to PAU in the family (Finger et al., 2010; Setlalentoa et al., 2010). Intimate Partner violence and relationship problems can negatively impact QoL (Brorsson, Ifer & Hays, 1993). Witnessing or being a victim of violence or intimate partner violence is associated with lower HRQoL (Campbell et al., 2002).

2.2.2 Psychological impact

2.2.2.1 Psychological impact on the individual.

PAU has also been reported to negatively impact an individual's psychological and mental health in many different ways, for example; daily stress (Ventegodt, Merrick & Andersen, 2003; Neupert et al., 2017), depression (Ginieri-Coccossis, 2007; Karpyak et al., 2016), dysthymia (Diaz et al., 2009), emotional regulation (Axelrod et al., 2011), Ptsd/ trauma (Najavits & Johnson, 2014; Killeen, Back & Brady, 2015), and anxiety (Worden et al., 2015). PAU is also associated with suicide and self-harm (Daly, 2006; Ginieri-Coccossis et al., 2007; Griffin et al., 2017). In similar way to physical health, if we look closely at how PAU can impact an individual's psychological health, we can further see how PAU can affect an individual's QoL. For instance, stress (Rapaport et al., 2002; Antoni et al., 2006; Colovic et al., 2009), depression (Stein & Barrett-Connor, 2002; Brenes, 2007; Andriopoulos et al., 2013), and anxiety (Stein & Barrett-Connor, 2002; Wetherell et al., 2004; Brenes, 2007) have all been reported to be associated with lower levels of QoL.

2.2.2.2 Psychological impact on the family.

Concerning the psychological impact that PAU can have on the family, there are various ways in which PAU impacts their psychological well-being. One of the principal outcomes of PAU in the family is an increase in stress (Orford, 1994; Mize Menees & Segrin, 2000; Kirby et al., 2005). It is also suggested that family members of PAU have decreased psychological adjustment (Kirby et al., 2005) and increased emotional insecurity (Orford et al., 2010; Tiwari, Srivastava & Kaushik, 2010). Anderson (2011) also outlined that partners of individuals with PAU often feel a profound sense of loss and hurt that can often lead to feelings of deep depression. Children living in a

family with PAU are more likely to witness family violence (Finger et al., 2010; Setlalentoa et al., 2010). What is more, children who witness domestic violence are more likely to have psychological issues in adulthood, for example, anxiety, social phobias (Mize Menees & Segrin, 2000), low self-esteem (Rydelius, 1997; Mize Menees & Segrin, 2000), and living with a feeling of fear (Kroll & Taylor, 2003).

2.2.3 Environmental/ Social impact

Along with the physical and psychological impact, PAU can also have adverse effects for environmental and social factors.

2.2.3.1 Environmental impact on the individual.

PAU can impact an individual's environmental health. For example, a clear link exists between PAU and homelessness. Research has reported that PAU can be seen as a cause of homelessness (Sosin & Bruni, 1997; Fountain et al., 2003; Ghose et al., 2013). While homelessness may also cause, maintain, or even worsen PAU (Fountain et al., 2003; Didenko & Pankratz, 2007). Hazardous drinking can also be associated with living on the street or in a shelter (Upshur, Weinreb & Bharel; 2014). These findings are important to note, considering that QoL can be lower for individuals with higher rates of homeless episodes (Gentil et al., 2019). Problem Alcohol Use is also associated with a higher probability of unemployment and a lower likelihood of being employed (Mullahy & Sindelar, 1996; Terza, 2002). In Ireland, Mongan (2016) found that the unemployed were two times more likely than the employed to have a positive DSM-IV score for dependence. This statistic is worth noting, as previous research has shown that QoL can be lower for unemployed people than those who are employed (Ytterdahl & Fugelli, 2000; Hultman, Hemlin, & Hornquist, 2006).

2.2.3.2 Social impact on the individual.

In terms of the social impact of PAU, research has shown that alcohol dependence is associated with a deterioration in social life (Ginieri-Coccossis et al., 2007), while PAU in old age has been found to be associated with social isolation and lower QoL (Lintzeris et al., 2016). Chou, Liang & Sareen (2011) investigated the association between social isolation and mood, anxiety and substance use disorders, and found that social isolation was positively correlated with alcohol abuse and dependence. Morito et al. (2015) found that social isolation could lead to mental disorders and alcohol use disorder. Social isolation is also seen to impact QoL. Those who are more socially isolated are seen to, in general, have lower levels of QoL (Hawton et al., 2011; Steptoe et al., 2013). Halford and Osgarby (1993) investigated PAU and marital problems. They found that PAU was related to more severe marital distress and a higher likelihood of divorce.

2.2.3.3 Environmental impact on the family.

Research has found that, if the family member is living with the individual with PAU, they are at higher risk for many psychological and physical factors discussed above (Schoenborn, 1991). PAU in the family has also been associated with unemployment (Mize Menees & Segrin, 2000), neglect (Grant, 2000), and poverty (Grant, 2000; Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010; Orford et al., 2010). According to the Psychiatric Morbidity Survey (2007), 8.5% of men and 3.0% of women with the lowest SES had experienced any symptoms of alcohol dependence in the previous six months; while 2.5% of men and 0.1% of women had experienced moderate to severe symptoms of alcohol dependence (Jones & Sumnall, 2016). These risk factors of having PAU in the family can further impact the QoL of the AFM. For example, in the previous sections, the association between unemployment and QoL have been noted (Ytterdahl & Fugelli, 2000; Hultman, Hemlin, & Hornquist, 2006). Another risk

factor, child neglect, was discussed in a meta-analysis by Norman et al. (2012), who provided evidence that neglected children had a higher risk of developing depressive disorders. The authors also reported that anxiety disorders, drug abuse, and suicidal behaviour were also associated with neglect. In terms of alcohol-related poverty, research shows a distinct association between the risks of alcohol-related death and SES (Jones & Sumnall, 2016), in that individuals with lower income are more likely to die due to their alcohol use or suffer from an alcohol-related disease (Makela, 1999, Romelsjo & Lundberg, 1996, Van Oers et al., 1999; Jones & Sumnall, 2016).

2.2.3.4 Social impact on the family.

Various social factors are also negatively impacted by PAU for family members. PAU or other problem behaviours in the family can cause distress in relationships (Kahler, McCrady & Epstein, 2003), and it is associated with lower marital satisfaction (Marshall, 2003; Floyd et al., 2006; Kishor, Pandit & Raguram, 2013) and higher rates of divorce (Rotunda, Scherer & Imm, 1995; Prescott & Kendler, 2001; Schneider, 2000; Collins, Ellickson & Klein, 2007; Setlalentoa et al., 2010). PAU can also cause social isolation of the family (Setlalentoa et al., 2010), and families living with PAU may lack friends (Tiwari, Srivastava & Kaushik, 2010). This isolation could be down to the idea that family members of PAU experience social stigma (Orford et al., 2013). Children from PAU families perform poorly in school (Rydelius, 1997) and are often socially isolated (Grant, 2000). Social factors are important as people tend to experience improved physical and emotional QoL when the needs for intimate relationships are satisfied (Myers, 2003). Research has also reported that marriage is associated with improved QoL scores (Han et al., 2014; Gutiérrez-Vega et al., 2018), while social isolation is associated with lower QoL (Hawton et al., 2011).

2.2.4 Other Factors Affected by PAU

There is little doubt that the relationship between PAU and QoL/ HRQoL is a complex one. Volk et al. (1997, p 899) stated that “the association between alcohol consumption and HRQoL is not well understood”. One factor that might extend these complexities, while also possibly helping to explain them, is comorbidity. It may be likely that, when individuals have problems in one area of life, they will have problems in other areas of their life. For example, individuals with PAU may also be likely to have problems in other areas of their lives. We have already discussed some of these areas above. For example, according to Byrne and Petry (2013), people living with HIV have a higher incidence of PAU when compared to the general population. The authors stated that, when those living with HIV had high levels of PAU, their QoL was negatively impacted. Other examples are found where those with PAU may have other problems related to health, such as cancer (Dguzeh et al., 2018) or liver disease (Tsochatzis, Bosch, & Burroughs, 2014), or psychological problems such as depression (Karpyak et al., 2016) or anxiety (Worden et al., 2015). Another significant area that comes under the heading of comorbidity is the use of, or the dependency on, other drugs, e.g. opioids. Research on comorbid opioid dependence was reported on a sample of methadone patients and found that excessive alcohol consumption was associated with QoL impairment (Sebanjo, Wolff & Marshall, 2006).

The list of “other” domains provided here is not exhaustive; the discussion above indicated that the concept of QoL is so widely researched that the number of potential domains could be vast and may apply to an individual with PAU and their family. Some examples of other domains that could be included to understand the impact of PAU on QoL might include; legal trouble (Rotunda, Scherer & Imm, 1995; Rydelius, 1997), employment (Terza, 2002) or intimate partner violence (Caetano, Schafer & Cunradi, 2017). Sexuality is

another factor that has the potential to impact QoL alongside PAU. Individuals in the LGBT community have high instances of alcohol dependence and depression, substance misuse and anxiety (McCann et al., 2013; Bockting et al., 2016) and lower levels of QoL compared to non-LGBT cohorts (Bockting et al., 2016).

Each category of domains above illustrates the complex area that is PAU and its impact on QoL, the profound impact PAU has on those with PAU and their families, and the need for quality treatment services for both the individual and each other member of the family that has been impacted. Therefore, it is essential to investigate these complex areas further to try and evaluate and improve the treatment options currently available to those living with PAU and their families.

2.3 Quality of Life and Treatment for PAU

Once a deeper understanding of QoL is achieved, it is hoped there will be benefits to treatment for individuals with PAU and their families. Part three of Chapter Two will examine the potential role of QoL in treatment, why to use QoL as a measurement in PAU treatment and, finally, a section on QoL measurement and QoL measurements specific to PAU.

2.3.1 QoL in Treatment

Quality of Life is viewed as a relevant concept in understanding PAU (Muller, Skurtveit & Clausen, 2016). There is a growing interest in understanding how QoL or HRQoL might help design quality treatment programs for PAU (Garner et al., 2014). When designing a PAU treatment program, the hope is for recovery and to prevent relapse. Traditionally PAU was viewed as a disease, and 'recovery' equated to abstinence; PAU is now viewed as a chronic

illness (McLellan, 2002; Laudet, 2011), and treatment design now looks at how the individual's overall QoL can be improved alongside abstinence (Laudet, 2011). The many domains that might be considered QoL can be categorised into Physical, Psychological, Environmental/ Social and Other (see Figure 1.1). These domains can help us understand how PAU can affect individuals and their families. Subsequently, treatment programs can include these areas as part of therapy to improve levels of QoL in identified domains. Laudet (2011) argued that QoL might help understand what is essential to the individual with PAU and their families that other addiction measures cannot capture. For the individual with PAU, improvement in domains of QoL can help influence recovery and relapse (Laudet, Becker, & White, 2009; Groshkova, Best & White, 2013), as lower levels of QoL are seen as a predictor of readiness for entering and continuing with a PAU treatment program (Muller, Kurtveit & Clausen, 2016).

Furthermore, the more time an individual is abstinent from alcohol, the more likely they are to see further improvement in QoL, and consequently, the likelihood of relapse decreases (Laudet, 2011). This 'knock-on' effect of improving QoL shows the importance of QoL in treatment design and the role of QoL in long-term care plans and different stages of the recovery process. By improving the QoL of the individual with PAU, the chance of recovery increases. Improvement in PAU will then help the QoL of the family members improve. Improvements in QoL in certain areas can affect the individual with PAU and their family. Therapy aimed to increase QoL in the family members can help improve coping skills, mental health and many other domains. Overall, QoL does have potential as an essential part of treatment design, as stated by Malet et al. (2006). They saw QoL as "an essential indicator in this multifactorial pathology for both the diagnostic and the therapeutic stages" (p. 183). Quality of Life can help identify areas that can improve well-being and

increase the likelihood of treatment engagement and success. QoL can also help us understand how to design effective and appropriate treatment for PAU.

2.3.2 The Importance of QoL in PAU Treatment

Research in the field of PAU traditionally focused on variables such as mortality due to alcohol (Babor, Longabaugh & Zweben, 1994), length of alcohol abstinence (Alessi & Petry, 2013), the number of alcoholic drinks consumed per day (Sullivan et al., 2007), and treatment program completion (Fernández-Montalvo et al., 2008). Clinical trials have generally based their primary endpoints on the quantity of alcohol consumed or the number/ percentage of days of abstinence or excessive drinking (Allen, 2003). However, this does not reflect the potential variances observed in more complex individuals, for example, those with irregular drinking patterns (Zywiak, Kenna & Westerberg, 2011). Research has revealed that only a quarter of alcohol treatment specialists favoured the above criteria as a gauge of success in clinical practice (Finney, Moyer & Swearingen, 2003; Luquiens, Reynaud & Aubin, 2011).

In light of the above, there has been a general shift towards using QoL as an outcome measure for PAU treatment evaluation. One way of explaining this is the shift from viewing PAU as a disease to a chronic illness. A paper by McLellan (2002) challenged how researchers viewed the treatment of PAU, stating that, while a large body of research existed on evaluation and treatment, their primary focus should be to stop alcohol consumption for this group, thus, seeing PAU as a disease that could be cured (McLellan, 2002). If PAU were to be understood as a chronic disease, abstinence could still be an ideal outcome, but reducing consumption would still be a positive outcome. However, treatment should not just be about gaining some improvement and leaving it at that; PAU should be viewed as a chronic illness with a continuation of care and intervention (Lahmek et al., 2009). White, Boyle and

Loveland (2002, p.8) stated that “chronic addiction disease emerges and intensifies through the interaction of multiple factors: the potency of the infectious agent (the drug), the biological and developmental vulnerability of the host; and the physical, political, economic, and social/cultural environment in which the person-drug relationship occurs.”

The last ten years or so have seen an increase in research in QoL concerning PAU (Levola et al., 2014; Costello et al., 2016). QoL is now viewed as a significant determinant when assessing an individual's PAU, well-being, contentment with life, and ability to function in different domains (Donovan et al., 2005). A review by Donovan et al. (2005) encouraged the use of QoL as an outcome measure in alcohol treatment research and described it as an essential factor in assessment, planning treatment and treatment outcome for PAU. Miller and Miller (2009) also identified the benefits of using a measure of QoL specific to alcohol misuse alongside the more traditional measures, such as abstinence, mortality rate and alcohol beverage consumption levels. Frischknecht, Sabo, and Mann (2013) found that individuals who reported abstinence or improved drinking presented significantly higher QoL scores than those whose drinking had not improved. Furthermore, Levola et al. (2014) revealed that interventions in alcohol treatment improved HRQoL and its domains, with reductions or cessation of alcohol use facilitating these changes for the most part. Measurement tools that focus on multiple life domains could help reveal a more holistic definition of recovery (Levola et al., 2014; Costello et al., 2016) and help understand chronic disease and PAU (Muller, Skurtveit & Clausen, 2016).

The interest in QoL and PAU treatment has led to an examination of existing QoL scales and how they can be used for evaluation. Laudet (2011) stated that "Subjective views on QoL help the clinician get a unique picture of how effective the treatment is" (p.44). The

use of QoL measurements in PAU has developed over time; in the latter half of the 1990s, a review of available articles on a Medline database reported that only 24 papers were published on QoL and PAU evaluation (Foster et al.1999). According to Malet et al., (2006), a review from 1998 to 2004 saw only four more papers in addition to the 24 initially cited by Foster et al. (1999). However, more researchers are recognising the benefit of using QoL as an outcome measure when evaluating PAU treatment (Finney, Moyer & Swearingen, 2003; Donovan et al., 2005; Miller & Miller, 2009; Levola et al., 2014).

2.3.3 Evaluating Treatment

Traditionally, investigations into treatment outcomes have focused on variables such as level of alcohol use, length of alcohol abstinence, and mortality due to alcohol (Babor, Longabaugh & Zweben, 1994; Allen, 2003). Moos (2018) argued that when assessing treatment for problem substance use, treatment programs are generally evaluated only in terms of broad categories and to evaluate treatment reliably, we need systematic methods that can measure the fundamental aspects of the treatment process. They argued that more emphasis should be on matching personal and program factors, and how particular patients match to a particular treatment program should be considered to help further understand treatment programs and their influence. Moos (2018) further argued that there should be a focus on how treatment environments differ in their impact on individuals who have varying concerns related to problem substance use. For example, even if consumption has not been reduced after completing a treatment program, other benefits may have been achieved. These benefits might include, for example, increased communication with a spouse, a better relationship with children, less antisocial behaviours, or improved access to healthcare and housing. All of these other potential outcomes could occur under the heading of QoL. Current

research identifies the need to understand QoL for PAU, and while there is a wealth of research in QoL concerning other health issues, the research specific to PAU is sparse.

Though QoL is considered to have great potential in understanding alcohol treatment programs, there are still several concerns present within the current research. For example, researchers in the area of QoL and PAU have indicated that there are issues when measuring QoL for PAU. In their review, Ugochukwu et al. (2013) argued that although alcohol-specific measures were theoretically better suited to investigate QoL in alcohol abuse and dependence, they seemed to have emerged as a way to examine particular areas of psychosocial impairment within particular studies. As a result, these measures would need further testing and validation within populations of those with alcohol abuse and dependence. The authors further highlighted measurement issues. For example, the severity of alcohol-related QoL deficiencies within the Alcohol Problems Questionnaire (APQ, Drummond, 1990) could not be investigated as the items on the scale were dichotomous. Furthermore, they reported that this scale's reliability and internal and external validity as a measure of alcohol-related QoL needed further investigation. In other research, Luquiens et al. (2015) reported that the QoL measurement, the AIQoL9, was the only disease-specific HRQoL instrument for alcohol dependence but contended that because it was derived from the SF-36, it lacked patient input.

2.3.4 QoL as an Outcome for Treatment Evaluation

Focusing on a variable such as QoL rather than just the traditional variables such as programme retention (Fernández-Montalvo et al., 2008; Wheeler et al., 2011; Nadkarni et al., 2017) and alcohol use levels (Wheeler et al., 2011; Morandi et al., 2017; Nadkarni et al., 2017), could be beneficial. However, in general, many of the methods used to monitor the

effectiveness of alcohol treatment do not provide sufficient evidence on how the treatment affects a client's QoL (Ryan et al., 2014; Palpacuer et al., 2015).

It seems that improvements in QoL are important for individuals with PAU and an important treatment goal (Luquiens, Reynaud & Aubin, 2011). However, the measurements that are currently being used to measure QoL might not be both relevant or accurate to the lives of these individuals, and obtaining measures such as these may be difficult as the variable of QoL is complex (Luquiens et al., 2012). While QoL has been researched in numerous studies of people with alcohol abuse and dependence, there is no consensus on its definition (Zubaran and Foresti, 2009). This point is especially true within alcohol use disorder treatment (Luquiens et al., 2012).

The QoL of individuals with PAU is not usually measured systematically. Limited research on how treatment changes QoL and the factors responsible for these changes need further systematic investigation (Srivastava & Bhatia, 2013). If QoL was further developed as a patient-reported outcome measure, it could help tailor treatment and improve the patient's clinical state and prognosis and their QoL (Srivastava & Bhatia, 2013). Therefore, QoL could be viewed as an essential outcome measure when investigating the subjective experience of an individual who has issues with alcohol and when attempting to quantify the psychosocial burden of PAU (Srivastava & Bhatia, 2013).

The interest in QoL as an outcome measure in alcohol treatment has advanced. However, in a systematic review from Luquiens et al. (2012), the authors stated that, although QoL was considered relevant to alcohol treatment research, there was a need for more data on the reliability, content, and sensitivity to change of QoL scales. Ugochukwu et

al. (2013) reviewed 50 studies over 40 years of research (1971 – 2011) on QoL and PAU. They revealed that 12 measures were adopted to investigate QoL in alcohol abuse and dependence. These 12 measures could group into two sub-categories: global measures (used in various disorders) and alcohol-specific measures. The authors found that while many general QoL measurements had been created and tested for reliability and validity, measurements specific to QoL and PAU have yet to be validated. They further argued that, as PAU can profoundly impact individuals and their families, extensive measures should be taken to quantify changes in the QoL of these groups.

Researchers argue that more in-depth measurements may be needed to create a complete picture of QoL for those with PAU. So, while the value of QoL has become more commonly accepted, standardised methods for its measurement still need further development in alcohol abuse and dependence research.

2.3.5 Discussion

This chapter discussed the concept of QoL, QoL measurement and QoL measurements specific to PAU, the impact of PAU on the individual and the family, and the potential role of QoL in treatment. Despite the complexities, there is support for a need to focus on QoL in PAU research (Srivastava & Bhatia, 2013; Ugochukwu et al., 2013). However, while support for QoL is present, there is no consensus on the type of scales to use in PAU research. Some research supports the idea of using general QoL measures. For example, Michael and Tannock (1998) suggested that when measuring QoL, measurements should be adjusted for the individual, with the QoL domains that are irrelevant to the individual removed and domains included or added that are more relevant to the individual. Others argued that general QoL measures allow a holistic approach to treatment (De Maeyer, Vanderplasschen

& Broekaert, 2010; Laudet, 2011). As discussed earlier, general QoL measures have emerged in PAU research with some success. However, other research calls for the development of QoL measures that address the domains relevant to the research population, i.e. individuals with PAU (Testa & Simonson, 1996). Within an Irish context, this is particularly important because of the unique role alcohol plays in the countries culture, identity, and socialisation (Stivers, 1976; O'Dwyer, 2001).

A systematic review by Luquiens et al. (2012) found that, although QoL was considered relevant to alcohol treatment research, there was a need for more data on the reliability, content, and sensitivity to change of QoL scales. In this review, the authors screened 331 articles and finally included 18 randomised, controlled trials of alcohol dependence. They reported that eight HRQoL measures were employed as outcome measures consisting of 27 life domains. These measures were generic (the SF-36, the scale most frequently used), and although six of the studies reported positive treatment effects, only one of the studies reported a significant HRQoL difference between intervention and control groups. The authors stated that it was challenging to compare QoL improvement between trials, as many different scales were used. Therefore, Luquiens et al. (2012) argued that a measure specific to PAU was needed.

Although the support for creating QoL measures specific to PAU grows, some research highlights that understanding an individual's QoL is still often overlooked in alcohol treatment programs (Ugochukwu et al., 2013; Ryan et al., 2014). The QoL of individuals with PAU is not usually measured systematically, and there is limited research on how treatment changes QoL, and the factors responsible for these changes need further systematic investigation (Srivastava & Bhatia, 2013). When a QoL measure specific to PAU is

developed, Barcaccia et al. (2013) argued that researchers tend to be more concerned with the reliability of QoL rather than having a clear understanding or definition of QoL. The ambiguity, and lack of consensus, on defining and measuring QoL raises many questions. For example, which is the best measure to use? What domains are essential for understanding the success of treatment? These are not straightforward questions.

Each domain was grouped thematically into overarching categories; physical, psychological, environmental, social and other. The frequency of domains for each category is represented in Figure 1.2 below.

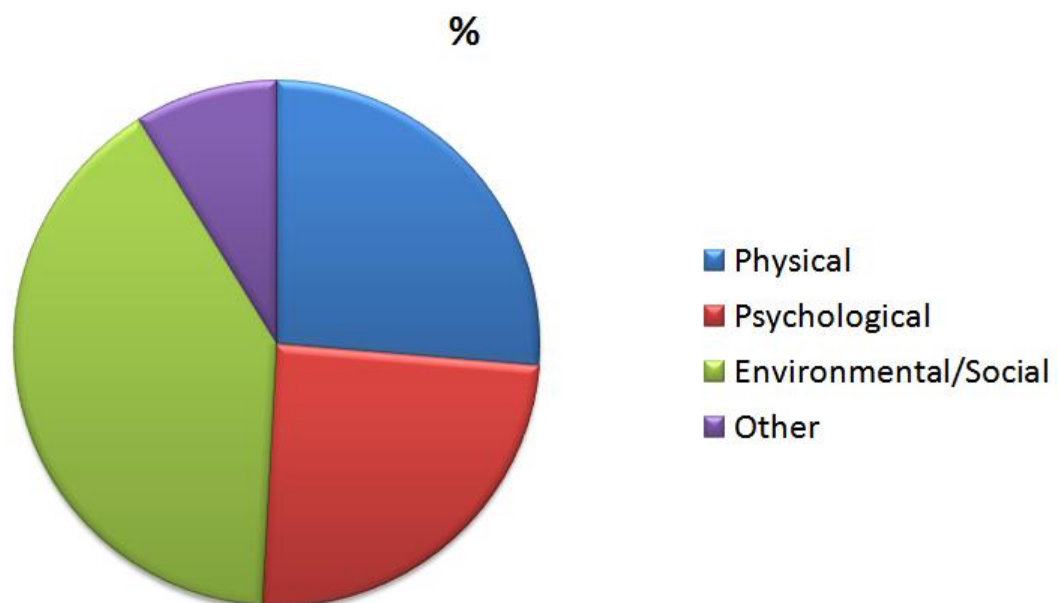


Figure 1. 2 Pie Chart showing frequencies for QoL domains in Table 1.1

Perhaps the category of ‘other’ raises even more questions. Which of the ‘other’ domains should be included? Which are important? Would newly developed questionnaires reveal more domains previously unlisted? Do specific domains apply more to certain populations?

These are complex questions, and the current study aims to take steps toward addressing some of these questions.

2.4 Conclusion

The literature reviewed definitions of QoL and highlighted the meaning that some individuals might give to QoL. It also highlighted the many issues faced when operationalising QoL concerning PAU and treatment. These issues form the main aim for this research, which is to investigate the meaning and experience of QoL for individuals with PAU and the AFMs of individuals with PAU. The literature illustrated the potentially severe impact PAU can have on QoL for the individual and their family and highlighted the need for adequate and effective treatment. Overall, the literature reviewed in this chapter highlights the growing belief that QoL is, as Malet et al. (2006) put into a clear statement, “an essential indicator in the multifactorial pathology for both the diagnostic and the therapeutic stages” (p.183). This Irish-based study is timely and significant especially as Ireland has such a strong association with alcohol culturally and socially (Stivers, 1976; O'Dwyer, 2001; Tilki, 2006). The findings will help researchers, treatment providers, and policymakers understand the true nature of the impact of PAU on the individual and the family in Ireland. Interviews will be conducted to collect data, while thematic analysis will be used to analyse the data. The next chapter will discuss further the research methodology, study design, data collection, and analysis.

Chapter 3: Methodology

The following chapter presents an account of the methodology used to address the aims of the study and considers some of the challenges faced. It discusses the theoretical framework and approach that guided the research before offering a justification of the chosen methods. This is followed by a discussion of the study design, sample, and procedures, including the data collection methods used in phases one and two, before the data analysis process is presented and discussed. Conducting a study among vulnerable participants, such as those living with PAU and the family members of those living with PAU, requires a sensitive and informed approach to planning and carrying out the research. Therefore, ethical considerations will be discussed, including participant and researcher safety. The chapter concludes with a short section on ensuring research quality.

3.1 Theoretical Framework and Study Design

The theoretical framework chosen for the current study is founded on social constructionism. This approach suggests that our ways of understanding the world may not always come from objective reality but from how phenomena are experienced or perceived by people (Burr, 2015). Social constructionism is multidisciplinary (Burr, 2015) and primarily involves interpreting the "processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live" (Gergen, 1985, p. 266). It endeavours to explain common forms of understanding as they exist in the present, in the past, and the future (Gergen, 1985), and it focuses on the "primacy of relational, conversational, social practices as the source of individual psychic life" (Stam, 1998, p. 199). This focus particularly suits the current study, where PAU not only has an impact on the individual's world but on those around them also, i.e. the family. Many social constructionists

maintain that there are as many realities as cultures, contexts, and ways of communicating (Raskin, 2002) and that there are multiple 'selves' constructed within the boundaries of these three domains (Gergen, 1991). Again, these factors relate to the current study where PAU is associated with cultural and social factors. Language may be the vehicle for our thoughts and emotions (Burr, 2015) and can play a significant role in social constructionism. How individuals speak about themselves and their world can help define the essence of their reality (Raskin, 2002). Also, importantly, social constructionism concerns relationships, in that an individual's reality is socially negotiated (Raskin, 2002), again, which suits the current study due to the influence PAU can have on both the individual and the family.

Within social constructionism, the study takes a qualitative approach based on interviews with individuals with PAU and the families of individuals with PAU to investigate the meaning and experience of QoL for both groups. Qualitative research is used when exploring the "social construction of reality" and when seeking to "understand the subject's point of view" (Wincup, 2017, p.4). It can simplify and manage data while acknowledging its complexities and context (Atieno, 2009) and can be used to investigate why or how a phenomenon occurs, develop theories, or describe the nature of an individual's experience (Fetters, Curry, & Creswell 2013).

Therefore overall, qualitative research can help us recognise the setting where particular behaviours occur by revealing contextual variables such as norms, traditions, roles, and values (Marshall & Rossman, 2014). It can further help to explore the processes and meanings of events by studying the frameworks within which individuals experience a setting or a process, the meanings they put on it, and how they interpret their experiences, thoughts, feelings and actions (Marshall & Rossman, 2014; Atieno, 2009). It helps uncover an

individual's inner experience and how their meanings are shaped through and in culture (Corbin & Strauss, 2008). This is helpful in the context of PAU in Ireland because of the tradition, culture, and social norms associated with alcohol use in Ireland and how those with PAU and AFMs experience or interpret these contextual variables and the meaning they give to PAU related behaviours, thoughts, or feelings.

QoL research often focuses on quantitative measures and treatment outcomes rather than individual experiences (Laudet, 2011). There is a scarcity of qualitative research in the literature that focuses on the meaning and experience of QoL for individuals with PAU. Furthermore, qualitative methods such as interviews may be helpful for a topic with sensitive nature such as PAU (Muraglia, Vasquez, & Reichert, 2020) as they can have therapeutic value and have the potential to facilitate healing and make positive changes due to emotional release that participants can experience during and after them (Rossetto, 2014). As participants share their stories and experiences, they may feel empowered or enhance their self-awareness, developing new insights into their issues, character, feelings, motives, or desires (Rossetto, 2014). Furthermore, interviews can help build a rapport between the interviewer and the interviewee. This rapport may reduce response bias by allowing participants to engage with the interview at a deeper level, thus providing more thoughtful and honest responses (Holbrook, Green & Krosnick, 2003). However, while there are benefits to interviews and qualitative research in general, it is also important to explore the disadvantages.

One disadvantage of qualitative research is that results are not tested to determine if effects/differences/ relationships between variables are statistically significant or due to chance. As a result, findings cannot be generalised with the same level of confidence that

results from quantitative analyses can (Atieno, 2009). Of course, this issue is only relevant if the research question requires such testing. Moreover, with qualitative research, there are generally smaller sample sizes, which further raises the issue of generalizability to the whole population of the research (Rahman, 2020). Generalisability is, however, not a goal of all research. Another perceived disadvantage to qualitative research is that stakeholders may favour quantitative research and view qualitative results as less credible when it comes to policy-making and using research for it (Rahman, 2020). Nonetheless, policy-makers can make sense of stories and other qualitative data once the data is rich and meaningful. Finally, data interpretation and analysis in qualitative research can be more complex, complicated, and time-consuming (Richards & Richards, 1994; Rahman, 2020). However, if these analysis methods are appropriate, they are necessary regardless of such challenges.

3.2 Sampling Approach

Sampling is the process of selecting people for a study to represent the larger population from which they came. A deliberately non-random method of sampling of a group of people with a particular characteristic, a common feature of qualitative research (Bryman, 2004), was chosen as the sampling method for this study. This purposive sampling method is a non-probability sampling that is most effective when studying a particular cultural or social domain (Tongco, 2007). This sampling technique's inherent apparent "bias" contributes to its effectiveness, and the method remains robust even when tested against random probability sampling (Tongco, 2007). This type of sampling method is widely used in qualitative research to identify and select information-rich cases (Palinkas et al., 2015). The sample is determined based on the idea that the individuals selected for the study are experts in a specific area.

In the present study, the inclusion criteria for both studies drew upon purposive sampling methods, however, there were different recruitment approaches for both phases. Phase one had purposive characteristics relating to the individuals having PAU (inclusion criterion), and participants were recruited through membership/ attendance of one of three active treatment programs. Phase two also had purposive characteristics in that the sampling approach drew on the inclusion criteria of individuals having a family member with PAU and self-identifying as not having a problem with alcohol. However, these participants were recruited through social media advertising. This method was deemed suitable given the potential difficulties in accessing family members in research (Navaie, 2011).

This study had a sample of 25 in total across two phases of research. Participants for phase one of the study were adults living in Ireland who self-identified as having a problem with alcohol use and have also been assessed as having a problem with alcohol use. Phase one had fifteen participants, evenly recruited from the Finglas Addiction Support Team (FAST), Ballymun Youth Action Project (YAP), and North Dublin Community Care Service, i.e., five participants from each organisation. Participants for phase two of the study were adults living in Ireland who had a family member or family members living with PAU. Phase two had ten participants recruited over the internet through social media advertising. Baker and Edwards (2012) argued that when deciding on a sample size in qualitative research, one of the central influencing factors is how many interviews are necessary to produce the desired outcome, that is, to meet the study's aim and objectives. Mason (2010) reported that the numbers required for qualitative interviews might vary greatly depending on the type of qualitative measures and publication. Samples in qualitative research tend to be small to support the depth of case-oriented analysis that is essential to this method of inquiry (Sandelowski, 1996). Sample sizes of 15 (phase one) and 10 (phase two) were considered

sufficient to provide "richly-textured information, relevant to the phenomenon under investigation." (Vasileiou et al., 2018, p.2). There was adequate data collected in the 25 interviews to investigate the aims of phase one, the meaning and experience of QoL of individuals with PAU and phase two, the meaning and experience of QoL of families of individuals with PAU. This conclusion was founded on numerous discussions with research supervisors and stakeholders.

As described above, participants from phase one were recruited from the community, facilitated by the Finglas Addiction Support Team (FAST), Ballymun Youth Action Project (YAP), and North Dublin Community Care Service. Recruitment through community settings was preferable, as interviewing in a more natural context in the community, rather than a more clinical setting such as a hospital setting, was an advantage. Participants were more familiar with this environment, which helped make the interviews as relaxed as possible. The three organisations helped identify suitable individuals for the study based on the clinical support staff's perception of the individual, initial and comprehensive assessments, and regular clinical team meetings and review meetings. These measures ascertained whether or not an individual had a problem with alcohol and ensured that particularly vulnerable individuals were not asked to participate in the study. When FAST/ YAP/ North Dublin Community Care Service identified a suitable person for the study, they brought the potential participant's attention to recruitment posters on-site in the FAST/ YAP/ North Dublin Community Care Service buildings. Alternatively, they sent an email to potential participants. The poster/ email described what was involved when participating in the study. After reading the information on the poster/ email, if an individual felt they might be interested in participating, they contacted the primary researcher directly through the contact information given to them by FAST/ YAP/ North Dublin Community Care Service or

through their key worker or counsellor. An arrangement was then made with potential participants to meet with the primary researcher at a suitable time at either FAST/ YAP/ North Dublin Community Care Service premises. The plain language statement (see Appendix A) and the consent form (see Appendix B) were given to participants before each interview. Inclusion criteria for phase 1 of the study were that participants were: aged 18 and over, self-identifying as having a problem with alcohol use, attending FAST/ YAP/ North Dublin Community Care Service and having been assessed by FAST/ YAP/ North Dublin Community Care Service as having a problem with alcohol use, fluency in English, and being cognitively healthy in order to consent (as clinically assessed by FAST/ YAP/ North Dublin Community Care Service). Exclusion criteria were those unable to make informed consent to participate in the study (e.g., due to cognitive capacity).

Participants from phase two were recruited over the internet through social media advertisements (see Appendix C). This recruitment method was preferred as all three organisations did not have access to family members affected by familial PAU. Facebook and Twitter accounts were set up specifically to advertise the study. Facebook advertisements were acquired while organisations related to PAU in Ireland retweeted the advertisement on Twitter. The advertisement briefly described what was involved when participating in the study. After reading the advertisement, if individuals felt they might be interested in participating, they contacted the primary researcher directly through the DCU email provided. The researcher then provided the potential participants with further information, including the plain language statement (See Appendix A). If the individual still wanted to participate, an arrangement was made to meet online at a suitable time. As this study phase occurred during the COVID-19 pandemic, interviews were online via Zoom. This method seemed to benefit participants as they seemed to feel more comfortable in their own homes,

which again helped facilitate the interviews to be as relaxed as possible. Inclusion criteria for phase 2 of the study were that participants were: aged 18 and over, self-identified as having a family member living with PAU, had fluency in English and were cognitively healthy to consent. Exclusion criteria were those unable to make informed consent to participate in the study (e.g., due to cognitive capacity) and those who may have had an alcohol problem themselves. Data collection for phase one occurred between January and March 2019. Data collection for phase two occurred between August and September 2020.

As the interviews progressed in phase one, participants began to echo what previous interviewees had spoken about in their interviews. Those participants who came closer to the end of the interview process in phase one expressed similar meanings and experiences of QoL as those participants earlier in the interview process. This issue was similar in phase two. Although not as apparent as in phase one, participants in phase two discussed similar meanings and experiences of QoL as the interview process progressed towards the final interviews. These outcomes may have been a result of data saturation, which Glaser and Strauss (1967: p. 61) defined as the following:

The criterion for judging when to stop sampling the different groups pertinent to a category is the category's *theoretical saturation*. *Saturation* means that no additional data are being found whereby the sociologist can develop properties of the category. As he sees similar instances over and over again, the researcher becomes empirically confident that a category is saturated.

Furthermore, in phase two, when internet adverts were applied, eleven potential participants made contact within the first week. One subsequently dropped out. However, beyond this initial first week of recruiting, no more participants made contact. Therefore, sampling

stopped after ten participants as it was more challenging to access the sample than in phase one, where participants had come from the three outpatient treatment programs.

3.3 Data collection

The data collection technique chosen for phases one and two of the study was one-to-one semi-structured interviews. An interview is a method of data collection that offers a natural way of interaction in various situations and that allows researchers to uncover data that may not be accessible through methods such as questionnaires or observations (Blaxter, Hughes & Tight, 2010; Alshenqeeti, 2014). Denscombe (2017) describes three main kinds of information elicited from interviews. These are:

1. An in-depth understanding of opinions, feelings, emotions and experiences.
2. A detailed understanding of complex issues and how things work, how factors are inter-connected, or how systems operate.
3. Privileged information from key individuals who can provide valuable insights and wisdom based on their experiences or positions.

Interviews also have the potential to yield rich data as the interviewer's presence presents the opportunity to rephrase or simplify a question that may not be understood by the interviewee, thus contributing to an enhanced mutual understanding that can uncover a more suitable answer to the interview question (Alshenqeeti, 2014). Furthermore, as researchers can now record responses with greater accuracy using any of the numerous recording devices available, the data can be reviewed as needed to produce an accurate report (Hermanowicz, 2002; Alshenqeeti, 2014).

3.2.1 Interview Process: Phase One

The researcher conducted the one-to-one interviews for phase one of the study in a private room on-site at FAST/ YAP/ North Dublin Community Care Service between January 2019 and March 2019. Upon each participant's arrival, the researcher offered tea/ coffee/ water. The researcher made sure to have an informal and polite conversation with the participant before the interview commenced to help make the participants feel at ease. The researcher then presented the participant with a plain language statement (see Appendix A) and a consent form (see Appendix B). The researcher then checked that participants thoroughly understood what the interview was about, that they were fully capable of giving consent, knew that participation was voluntary, and finally, could withdraw at any stage without explanation. Then, those who wished to continue participating in the study were asked to sign the consent form. The original copies of these forms were locked in a cabinet. If a participant appeared intoxicated or unfit to participate in the interview for any other reason, the researcher would have followed guidelines as per the organisation's (where the interview occurred) policies and procedures. These steps included

- explaining the organisation's policies and procedures to the participant
- rescheduling a time for another interview
- withdrawing from the interview room
- liaising with and notifying the participant's key workers and other clinical support staff

When the interview concluded, participants were given a debriefing sheet. After the participant was debriefed and left the room/ online room, the researcher noted any observations or thoughts about the interview. All data obtained during the interviews were transcribed verbatim as soon as possible after the interview.

3.2.2 Interview Process Phase Two

The researcher conducted the interviews for phase two online between August and September 2020. Interviews took place on Zoom. Again, it was essential to consider the location of the interviews to ensure privacy and confidentiality for the participant. All correspondence was conducted through email before the interviews, including sending plain language statements and consent forms and getting them signed before the interview. Interviews lasted for approximately 40 min to 1.5 hours and were recorded on Zoom and another mobile audio recording device.

The researcher made sure to have an informal and polite conversation with the participant before the interview commenced to help make the participants feel at ease. They then reminded the participant of the plain language statement and consent form, which had been previously sent by email and had already been signed and returned. The researcher then checked that participants thoroughly understood what the interview was about, that they were fully capable of giving consent, knew that participation was voluntary, and finally, could withdraw at any stage without explanation.

When the interview concluded, participants were sent a debriefing sheet by email. After each interview, the researcher noted any observations or thoughts about the interview. All data obtained during the interviews were transcribed verbatim as soon as possible after the interview.

3.2.3 Interview Schedules

All interviews in both phases included a standardised open-ended interview schedule consisting of three sections. Each section had several key questions, along with secondary

questions. Guided questions were used to help conduct the interview and re-direct it if it went off-track or off-topic, often occurring during interviews (Tong, Sainsbury & Craig, 2007). All questions were open-ended to acquire as much data as possible and encourage participants to give complete information. Participants in each phase of the interviews respectively were all asked similar semi-structured questions (Turner III, 2010) to respect "the way the participant frames and structures the responses" (Marshall & Rossman, 2014, p.150). The semi-structured approach enabled the same questions and prompts across the interviews and left them sufficiently open should a participant wish to bring up something relevant that the researcher had not considered. The interviews were led by participants, although prompts, influenced by domains taken from quantitative QoL research by Costello et al. (2016), were used to keep the interview on track. These domains included substance use, mental health, psychological wellness, physical wellness, social wellness, occupational wellness, daily life functioning, continuing care programs/services engagement, and overall QoL or life satisfaction. The interview guides can be viewed in Appendix D.

In phase one, the first section of the interview focused on alcohol use, previous and current treatment for alcohol use, other substance use, previous and current treatment for other problem behaviours, and finally, what prompted the participant to access their current treatment programme. Questions about previous treatment are essential to take account of the possibility that the participant's understanding of QoL, and the perceived effect of alcohol on this variable, has already been influenced by previous treatments. Relapse can be common for those with PAU (Walton et al., 2003, Zywiak et al., 2006), particularly for comorbid alcohol and mental health issues (Bradizza et al., 2009). Hence, the researcher deemed these questions important as some participants may have experienced treatment already. The second section focused on understanding what QoL meant to those with PAU and how they

experienced it in their daily lives. This section focused on the participants' understanding of QoL and what they believed was essential for themselves or someone else to have a good QoL. This section also investigated the participants' experience of well-being, life satisfaction, daily thoughts, moods and behaviours, and how they go about their daily tasks. The third section of the interview focused on how alcohol had affected the individual's QoL, how it had affected their thoughts/ moods/ behaviours, how it had affected their daily life functioning, and how it had affected their relationships. It also focused on how other substances had affected the same. See Appendix D for the interview guide for phase one interviews.

The first section of interviews in phase two focused on the AFMs and their family members' alcohol use (or any other substance use/ problem behaviour), previous and current treatment for the individual with PAU or the AFM, and finally, what was it that prompted the AFM to access their current support network, if applicable. The second section focused on understanding what QoL meant to AFMs and how they experienced it in their daily lives. This section focused on the participants' understanding of QoL and what they believed was essential for themselves or someone else to have a good QoL. This section also investigated the participants' experience of well-being, life satisfaction, daily thoughts, moods and behaviours, and how they went about their daily tasks. The third section focused on how the individual's alcohol use had affected the family member's QoL, their thoughts/ moods/ behaviours, their daily life functioning, and how it had affected their relationships. It also focused on how other substances had affected the same. See Appendix D for the interview guide for phase two interviews.

3.4 Data analysis

The researcher transcribed all interviews verbatim from phases one and two as soon as possible after the interviews were completed. The completed transcripts were checked with the audio files to ensure that the transcription was accurate and that there was no identifiable information or spelling mistakes. Each transcript was reviewed numerous times to ensure that the researcher was intimate and highly familiar with the data. Although time-consuming, actively reviewing the transcripts in this way is a process that promotes a deeper understanding of the data and is seen by researchers to be an essential part of the interpretation stage of analysis (Braun & Clarke, 2006). Transcripts were transferred to NVivo for coding.

Each dataset was analysed thematically. The analysis method chosen to find meaningful patterns in the data was Thematic Analysis (TA), the six-phase framework developed by Braun and Clarke (2006). Braun and Clarke (2006, p. 79) described TA as "a method for identifying, analysis and reporting patterns (themes) within data". However, they further argued that there is more to it than this definition. Phases one and two of this study aimed to understand the QoL of individuals with PAU and families of such individuals inductively by building an understanding of it from the bottom up. An inductive approach to qualitative research such as this is data-driven (Braun and Clarke, 2006). This means it looks at the themes purely within the data themselves, rather than taking knowledge of QoL from other areas that might dictate a more theoretical or top down approach. In inductive research, various perspectives are drawn together to form a conceptual framework that is robust enough to guide the study (Liehr & Smith, 1999). Consequently, research that centres on deductive reasoning use pre-existing theories, whereas research centred on inductive reasoning tends to be 'theory-building' (Imenda, 2014). Braun and Clarke (2006) outlined

how inductive analysis is the process of coding the data and not trying to make the data fit into pre-existing conceptions or coding frames. The process of analysis for the current study is outlined in Table 2.1 below.

After the six steps below were undertaken, an interpretative analysis phase followed, where the primary themes and subthemes were discussed along with existing theory and literature. At the end of each interview, the researcher documented any moments they felt were significant, such as body language or mood, by taking some reflexive field notes when the participant left the room/ online room. This process was valuable as these field notes were considered and analysed alongside the recorded speech, which helped with the thematic data analysis. These reflexive field notes mainly focused on:

- The mood or demeanour of the participant at different stages of the interview
- How obliging they were to do the interview
- How comfortable they seemed to be there
- The body language of the participant
- Was the participant intoxicated (phase one)?
- Was the participant inhibited in any way? i.e., was there a sense that they were being watched or listened to by someone else during the interview (phase two online interviews)
- Notes were also taken on how the researcher felt during and after the interview

Table 2. 1

Phases of Analysis based on Braun And Clarke's (2006) Six-Step Approach

Phase	Description of Process
1. Familiarisation with the data	Familiarisation with the data began before and during the transcription stage of the

	interviews. The recordings were listened to again before transcription, and then during transcription, notes were taken to document initial thoughts and potential themes.
2. Generating initial codes	In the second phase, codes were systematically attached to sections of the data, i.e., words or sentences, across the entire dataset.
3. Generating themes	After determining the initial codes throughout the dataset, related codes were grouped and sorted under potential themes.
4. Reviewing potential themes	All these groups were reviewed and revised to ensure they made sense concerning the study's investigation. This step involved reviewing the study's aim and objectives and ensuring that the themes were relevant to them. At this stage, some prominent themes and extensive pieces of coding were omitted as they were seen to be mediating factors in QoL rather than part of QoL itself, for instance, the themes of resilience and coping.
5. Defining and naming themes	This fifth phase involved generating titles and definitions for each theme and sub-theme and ensuring that these sub-themes interacted and related to the primary theme.
6. Producing the report	Each theme was then discussed separately, using clear examples of quotes to illuminate the findings. Trustworthiness of findings was ensured by checking the analysis at each stage with the research supervisors

Braun et al. (2018) and Braun and Clarke (2019; 2022) discuss and outline three main analytical approaches to thematic analysis. These are coding reliability thematic analysis, codebook thematic analysis and reflexive thematic analysis. Coding reliability thematic analysis involves multiple coders who must discuss and agree on the codes. This approach can result in improved inter-coder reliability and less subjectivity or bias from having only one coder. Codebook thematic analysis is a deductive approach to thematic analysis that uses structured codebooks and predetermined codes. These codes and codebooks are usually drawn from a review or an initial analysis of the data. The third approach outlined by Braun

et al. (2018) and Braun and Clarke (2019; 2022) is reflexive thematic analysis, which is the approach used in the current study. This approach is the most flexible of the three analysis types and does not use predetermined codes or codebooks. The reflexive approach provides the flexibility to change, remove, and add codes as the data is analysed, and it allows the themes to be inductively generated from the bottom up. Reflexive thematic analysis recognises the researcher's position within the analysis and views their role and contribution as necessary and unavoidable. The approach acknowledges factors such as the researcher's values, beliefs, ideas, experiences, knowledge, and social position, and critically examines how these factors influence the research process, particularly the data analysis. Throughout the research process, reflexive notes were taken to consider these factors, with the motive to build the codes from the bottom with minimum bias.

Braun and Clarke (2012; 2014; 2021) also highlighted some theoretical assumptions that should be addressed when conducting TA (see Table 2.2). These are:

- essentialist versus constructionist epistemologies
- experiential versus critical orientation to data
- inductive versus deductive analyses
- semantic versus latent coding of data

Table 2. 2 Theoretical assumptions addressed when conducting Thematic Analysis

Essentialist versus constructionist epistemologies.	A constructionist epistemology was adopted. While the importance of recurrence in the data was acknowledged, meaning and meaningfulness were the main criteria in the encoding process.
Experiential versus critical orientation to data.	An experiential orientation was adopted. The study aimed to prioritise individuals with PAU and the family members of individuals with PAU's accounts of their attitudes and opinions or their meaning and experience of QoL.

Inductive versus deductive analyses.	A predominantly inductive approach was adopted. The data was open-coded with emphasis on the participants'/ data based meanings. However, deductive analysis was also used to ensure that coding and themes were relevant to the research questions.
Semantic versus latent coding of data.	Both semantic and latent coding were adopted. Semantic when only presenting the data as communicated by the participant and latent when interpreting codes and themes and determining which are relevant to the research question.

3.5 Ethical considerations

In line with the four principles set out by the Psychological Society of Ireland (PSI, 2022), the researcher sought to promote respect for the rights and dignity of others, competence, responsibility, and integrity throughout this study. Steps included being honest, fair and respectful of others, honouring and promoting all participants' fundamental rights, dignity, and worth, and respecting their rights to privacy, confidentiality, self-determination, and autonomy, consistent with the law. The researcher endeavoured to maintain high standards of competence in their research and acknowledged any limitations to their particular competencies. They ensured to provide only those services and use only those methods for which their education, training or experience qualified them.

Participant confidentiality was of particular concern. Conducting research in Ireland with a small sample from a community-based population makes the principles of confidentiality more demanding, especially due to the sensitive nature of the topic. As far as possible, confidentiality and anonymity were assured. All personal information given as part of the study was kept confidential, and the researcher consistently reiterated the confidential nature of the study to participants before the interviews. The legal limitations on

confidentiality were also explained in detail to all participants. There is a fine line between "sufficient contextual information and preserving anonymity." (Wincup (2017, p.55). Therefore, throughout the study, the researcher was vigilant about protecting participants' identities and only documented the participants' first names on the recording. Participants were assured that, during the transcription process, pseudonyms were to be used, and any specific identifying details were also going to be changed. Furthermore, all participants' names and demographic information were stored separately, and all transcripts were password protected on the researcher's computer.

Before each interview commenced, all potential participants were guided to read the plain language statement (see Appendix A) and the consent form (see Appendix B) and discuss any questions they might have had. Participants were also given a choice for the forms to be read aloud. This step was taken in case any participants had literacy issues around reading or comprehending written words. All participants signed the consent form before the interview began. These forms were stored separately from interview transcripts. It was essential to ensure that no participant felt obliged to participate in the study. Therefore, it was made explicit to participants that participation in the study was voluntary and that they were free to withdraw at any stage before or during the interview without giving a reason.

Throughout the study, participants' trust was of the utmost importance. It was held with the highest ethical principles from the beginning at informed consent to the end when the research was completed, and the data and interview transcripts were stored securely. Establishing trust early in the research was an essential part of the process as it helped the interviewee to feel at ease. This trust was essential, particularly in a study like this, where the data collected is of a sensitive nature.

Problem alcohol use can be considered a sensitive topic, and there is potential for an individual to become distressed when talking about their experience of living with it. However, while some participants may have experienced distress during or after the interview, and while this was taken seriously, it should be noted that distressed individuals can also still feel like they have benefitted from taking part in the research. A study by Cromer et al. (2006) found that individuals who experienced distress by answering a survey comprising personal questions tended to be nevertheless optimistic about their participation in the study.

With this in mind, during interviews, the interaction between the interviewer and the interviewee is of great importance. Therefore, while acknowledging the sensitivity of the research topic, the researcher adopted a free-flowing conversational style throughout the interviews. This approach created a natural atmosphere and helped the interviewees to feel at ease so that their accounts were collected as accurately as possible. Towards the end of the interview, the tone of the questions became more hopeful. It focused on participants' hope for the future to leave participants feeling more positive, as advised by Van Ginneken (2014).

It was essential to consider the location of participant interviews when trying to ensure privacy and confidentiality. For phase one, in each building, counselling rooms were used where only the researcher and the participant were present. Before each interview, the researcher arrived with enough time to ensure that the room was suitable for the interview. The trained professional staff at FAST/ YAP/ North Dublin Community Care Service were also aware of when and where interviews occurred. They were also available to provide professional support and guidance to participants if they became upset during the interview.

This measure was to ensure safety for both the participant and the researcher. For phase two, the researcher made sure that the interviewee was comfortable in their environment before proceeding. Specific protocols for dealing with participant distress, researcher safety and safety online were devised in line with best practice.

3.5.1 Participant Safety

All potential participants were made aware of the potential risks associated with the interviews. This information was included in the PLS and was discussed verbally with the participant before written consent. Potential risks to participants can include unpleasant feelings, emotions, or traumas triggered by the interview questions. Problem alcohol use is associated with factors such as mental health issues (Graham et al. 2016), homelessness (Upshur, Weinreb & Bharel, 2014), IPV (Schumm et al. 2009), drug use (Teesson et al. 2010), and HIV (Van Dyk, 2012). Although the interview questions did not focus on those specific areas, there was a chance that such topics could arise during the interview. Therefore, it was essential to provide a comprehensive list of phone numbers of organisations that could help people deal with these particular issues while also ensuring that the participants were directed towards organisation key workers, counsellors, and other clinical support staff if required. At the end of the interviews, all participants were given a debriefing sheet containing these telephone numbers and information on accessing counselling support from the appropriate supports, if needed. The debriefing sheet also provided information on obtaining the study results when it was completed.

The researcher was always mindful of possible illness or fatigue during the interviews (Turner III, 2010). the researcher continuously checked in with participants to ensure that they were comfortable and happy to give their consent to continue with the interview. If a

participant got upset, the researcher checked if they were ok to continue the interview. If they were not ok with continuing, the researcher would have debriefed them and reminded them that participation was entirely voluntary and that there were no consequences for withdrawing. The interview would then end. However, while some participants got upset during the interviews, everyone was happy to continue. Participants who became upset were guided to liaise with and seek help from their key workers and other clinical support staff with whom they had a good rapport. They were also directed to the list of telephone numbers on the debrief sheet that they could use if they felt the need.

If a participant decided that they were uncomfortable being recorded, the researcher had planned to offer to use pen and paper to document the data instead. If they were still not happy to continue after this, the interview would have ended. However, in the current study, everyone was happy to be recorded. This process is a standard procedure in qualitative research, where someone is not happy to have his or her voice recorded. The implication for this type of data collection is that relevant thematic material can still be extracted from shorthand notes of someone's speech; however, verbatim quotations may not be used.

It was considered that a participant may turn up for the interview and appeared intoxicated or unfit to participate for any other reason. In that case, the researcher had planned to follow guidelines as per policies and procedures set out by the organisations. These steps included explaining the organisation's policies and procedures to the participant, rescheduling a time for another interview, withdrawing from the interview room, and liaising with and notifying the participants' key workers or other clinical support staff.

While the study was not investigating illegal activities, there was the potential that information relating to illegal activity could have been disclosed. In line with PSI guidelines (PSI, 2022), the limits of confidentiality were explained in full. Participants were made aware of this limitation in the PLS and verbally at the beginning of each interview. If information highlighting illegal activities or potential dangers to the participant or another person were disclosed, this information would be relayed to the professional staff at the organisation or the relevant authorities.

Obtaining informed consent from participants further reduced risks. All potential participants were informed of their right to; withdraw from the interviews at any stage of their involvement without consequences; identify feelings of distress to the interviewer; expect a sensitive and respectful response from the interviewer; receive follow-up after the interview should the need arise. Furthermore, it was made clear to participants that only direct quotes would be applied and interpreted in the data and that these quotes would only be used in the context that the participant intended.

Concerning power relations, it was made clear that the interviewer was a student and was in no way in a position of authority with no power over the participants' support, care, or treatment. By understanding that these participants could be vulnerable, all necessary measures were put in place to ensure that they had all the necessary support if they felt they needed it.

Participants with PAU or the families of such individuals may be considered vulnerable. PAU can be associated with mental health issues and reduced cognitive capacity. Therefore, there can be mental health vulnerabilities. However, safeguards were put in place

to ensure that particularly vulnerable individuals were not asked to participate in the study. FAST, YAP and North Dublin Community Care Service helped identify individuals suitable for the study based on the clinical support staff's perceptions of the individual, initial and comprehensive assessments, and regular clinical team meetings and review meetings. These measures ascertained whether or not the individual had a problem with alcohol use while also ensuring that particularly vulnerable individuals were not asked to participate in the study.

3.5.2 Researcher Safety

As there was sensitive or personal information disclosed during interviews, the researcher made sure to protect themselves from any problems that could arise from this. First of all, through the PLS and verbally, the researcher made sure that participants were fully aware of the limitations to their confidentiality. If the information disclosed revealed harm to the participant or another, then that information would be passed on to the relevant authorities. Furthermore, the researcher clearly explained data protection protocols to all participants before acquiring consent. These steps protected against any legal issues that could arise.

As the researcher was exposed to potentially upsetting or disturbing information, the researcher made sure that they checked in regularly with academic supervisors. At the same time, they also discussed matters with a counsellor.

During interviews, there may have been a risk of transference, leading to over-familiarity, over-dependence, or even violence due to stress or mental health difficulties (Moyle, 2002). A professional relationship was set up to minimise this risk of transference. Furthermore, personal information was never shared with participants. This information included personal email, phone numbers, or social media accounts. The researcher did not reveal any information on their opinions, attitudes, behaviours or experiences. They were

always dressed suitably for the interviews, were aware of their body language, and kept a professional distance from participants.

Staff at FAST/ YAP/ North Dublin Community Care Service knew when and where interviews were taking place. The researcher also had an agreement with the staff at the organisations that if they did not hear from them after a fixed period, they would check on the interview room. To reduce any risks to personal safety, the researcher always used a separate phone and email address for correspondence. The researcher attended regular supervisor meetings and counselling sessions to ensure psychological safety. Interviews were spaced with adequate time between each one so the researcher could process what was said and disclosed.

If a participant appeared intoxicated or unfit to participate for any reason, the researcher had planned to follow guidelines as per policies and procedures set out by the organisations. These steps included explaining the organisation's policies and procedures to the participant, rescheduling a time for another interview, withdrawing from the interview room, and liaising with and notifying the participants' key workers and other clinical support staff.

3.5.3 Ethical Approval

Research with vulnerable participants such as individuals with PAU or family members of those with PAU is complex and has ethical challenges that require sensitive planning. Dublin City University requires that all research involving human participants receive ethical approval, so both phases of research were subject to appraisal by Dublin City University's Research and Ethics Committee (DCUREC). Gaining ethical approval for phase one lasted

two months, with an initial proposal sent in on the 5th of October 2018 and DCU REC approval arriving on the 3rd of December 2018. Gaining ethical approval for phase two took longer, with an initial proposal sent in on 1st November 2019 and DCUREC approval arriving on 16th January 2020. There were also further amendments due to COVID-19, which lasted from 13th July 2020 to 17th July 2020.

3.6 Ensuring Research Quality

It was important to demonstrate and ensure research quality and rigour during the study, including *credibility*, *transferability*, *dependability*, and *confirmability* (Lincoln & Guba, 1985). To ensure *credibility* and confidence in the truth of the findings, the researcher had already developed an early familiarisation and engagement with participants through several work placements and through regular meetings with the research stakeholders. The researcher also regularly discussed the data analysis process with their supervisors. The supervisors guided the researcher to ensure that the themes made sense concerning the study's participants and research aims. These regular meetings and discussions also helped ensure *dependability* and that the findings were consistent and could be repeated by determining intersubjective dynamics between the researcher and the participant to minimise implicit bias. Discussions by email and regularly reviewed documents with feedback from supervisors also formed an audit trail of the decision-making process. These measures helped ensure the *confirmability* of the study. Detailed descriptions of the study's context and assumptions central to the study ensured *transferability*.

3.7 Methodology Conclusion

This chapter introduced and explained the methodology for this study. The study set out to qualitatively investigate the meaning and experience of QoL for individuals with PAU and the family members of individuals with PAU in Ireland using Thematic Analysis for data analysis. The rationale for this approach was explained, and the research process, including recruitment, data collection and ethical issues, was presented. The next chapter presents the study findings of phase one.

Chapter 4. Findings from Phase One

This chapter presents the findings of the first phase of data collection, involving 15 interviews with adults who self-identified as having a problem with alcohol use. The chapter presents the analysis of themes identified from the participants' interview data in thematic format. The analysis addresses the aims of this phase of the study which were to understand what quality of life (QoL) means to individuals with problem alcohol use (PAU) living in Ireland, and to explore how these individuals experience QoL in their daily lives.

4.1 Profile of Participants

Fifteen adults consisting of nine male respondents and six female respondents who were recommended by the Finglas addiction support team (FAST), Ballymun Youth Action Project (YAP), and North Dublin Community Care Service, because they self-identified as having a problem with alcohol, took part in interviews between February 2019 and April 2019. The average age of respondents was 41 years ($SD = 9.38$, range = 53–27). The first six interviews in Table 3.1 took place in fast in Finglas and recruitment was supported by staff at fast. The next five interviews took place in yap in Ballymun and recruitment was supported by staff in yap. The final four interviews took place in the North Dublin Community Care Service in Swords and recruitment was supported by the staff there. Five male participants and two female participants reported that they had problems with other drugs alongside alcohol, two male participants and two female participants reported using other drugs but that they were not a problem, while two male participants and two female participants reported no other drug use. Table 3.1 contains more information about each participant.

Table 3. 1

Phase One Participant Information

Pseudonyms	Sex (m/f)	Age	Site	Drugs/ substances used/ using with alcohol	Other psychological issues (self- reported)	Medication	Length of sobriety at time of interview
Chloe	F	29	Fast	Dabbled in other drugs but did not self- identify as having a drug problem	Eating disorder, low mood, self- harm, suicidal tendencies.	No	About 2 weeks sober
Tracy	F	38	Fast	No	Depression	No	Still having the odd drink on Saturday nights
Robert	M	37	Fast	No	Depression, OCD, health anxiety	Anti- depressants (Lexapro)	About 1 month sober
Daniel	M	46	Fast	Cannabis but self-identifies as not having a cannabis problem	Depression, anxiety, gambling	No	About 2 weeks sober
Luke	M	50	Fast	No	Anxiety, sleep issues, trauma	No	About 10 days sober
Liam	M	53	Fast	Has taken drugs but did not self- identify as having a drug problem	Anxiety, panic attacks	Medication in the past for anxiety	Drank the night before interview
Conor	M	48	BYAP	When drinking takes any available drugs	Gambling, any other potentially addictive behaviour	No	Drank just before interview
Bernadette	F	45	BYAP	Has used a wide variety of drugs including Valium and heroin	Gambling	Yes	About 4 days sober
Adam	M	48	BYAP	Cocaine	Hearing voices, hallucination s, paranoia	Anti- psychotic medication	Still having two drinks every Thursday

Jack	M	31	BYAP	Cocaine, cannabis, 'tablets' (benzodiazepines)	Depression	No	Drank the morning of interview
Emily	F	45	BYAP	Cocaine	Anxiety	No	About 2 days sober
Grace	F	27	Swords	No	Anxiety, depression, OCD	For depression and sleeping	About 1 week sober
Tadhg	M	53	Swords	Cocaine	Depression, anxiety, suicide attempts	For depression and anxiety	About 15 weeks sober
Hannah	F	31	Swords	Used cannabis in the past but not anymore	Sex addiction, depression, anxiety, panic attacks	For anxiety	About 10/ 11 months sober
Mark	M	29	Swords	Cocaine	No	No	About 2 weeks sober

4.2 Chapter Layout

See Table 3.2 for a summary of the themes and associated subthemes in phase one. In the analysis that follows, participants' quotes are provided to illustrate the themes; as described above, these participants have been allocated a pseudonym (of the same sex) to protect their identity. The following sections will report on each theme in detail. Section one gives the findings on participants' meaning and experience of QoL concerning their mental health and emotional wellbeing experiences related to FPAU. Section two gives the findings on participants meaning and experience of QoL concerning social connectedness. Section three gives findings on participants meaning and experience of QoL in relation to socioeconomic factors. Section four is devoted to an in-depth review of the findings on physical health. Finally, section five introduces the findings of altered daily life functioning.

4.3 Themes from Phase One Findings

Data analysis of this phase of the study involved the categorisation of the findings into five main themes underpinning how QoL was understood and experienced by individuals with problem alcohol use. These themes were mental health and emotional wellbeing, social connectedness, socio-economic factors, physical health, and altered daily life functioning. See Table 3.2 for a summary of the themes including subthemes. In the analysis which follows, quotes from participants are provided to illustrate the themes; these participants have been allocated a pseudonym (of the same sex) to protect their identity.

Table 3. 2

Summary of Themes and Subthemes for Phase One

Themes	Sub themes	Notes
Mental Health and Emotional Wellbeing	<i>The adverse effects of alcohol use on mental health and emotional wellbeing</i>	For example: shame, anxiety, low mood, potential for suicide, regret, hopelessness, negative thinking, emotional comedown...
	<i>Drinking alcohol to improve mental health and emotional wellbeing</i>	For example: drinking for confidence, drinking to relieve anxiety, drinking to relieve stress, drinking to deal with feelings, drinking to forget traumas
	<i>Consequences of recovery from PAU for mental health and emotional wellbeing</i>	For example (positive): positive outlook, positive thinking, positive feelings or emotions, expression, openness For example (negative): feeling unsupported in treatment, feeling 'raw' in early recovery, difficulty of learning how to live without alcohol
	<i>Goals and desires for mental health and emotional wellbeing</i>	For example: taking time to self, improved mood, peace, gratitude, self-confidence, self-acceptance, more meditation/ mindfulness, more positive outlook
Social Connectedness	<i>Negative impact of PAU on relationships</i>	For example: losing connection with others, being dishonest, conflict, unreliable to others, worrying or embarrassing others, letting others down
	<i>Drinking alcohol to connect with others or to alleviate social disconnection</i>	For example: isolation, loneliness, relationship dysfunction, breakups, death of a loved one, societal factors, normalisation of drinking, social pressure
	<i>Consequences of Recovery or Sobriety for Social Connectedness</i>	For example (positive): making amends, helping others, connecting with others) For example (negative): losing friends due to not drinking, fear of social situations)
	<i>Goals and desires for relationships and connection to others</i>	For example: to make amends, improved connection, get

		support, more compassion, acceptance, validation
Socio-Economic Factors	<i>Goals and desires for socio economic factors</i>	For example: goals for housing, job, finances, education
	<i>Negative outcomes of PAU on socio-economic factors</i>	For example: impact on housing, education, finances, career, job
	<i>Benefits of recovery for socio-economic factors</i>	For example: benefits for education, career, housing, finances
	<i>Culture, Society, and Environmental factors</i>	For example: drinking culture and normalisation of drinking, government policy
Physical Health	<i>Negative physical outcomes of PAU</i>	For example: alcohol withdrawal, hangovers, blackouts, falling, injury, health
	<i>Drinking alcohol to ease physical discomfort</i>	For example: physical pain, hangover, withdrawal, sleep, physical cravings
	<i>Physical benefits of recovery from PAU</i>	For example: physical health improving, eating better, sleep improving
	<i>Goals and desires for physical health</i>	For example: to get fitter and healthier, to eat healthier
Altered Daily Life Functioning	<i>Negative impact of PAU on daily life functioning and benefits of recovery</i>	For example (negative): lack of motivation around daily tasks For example (benefits of recovery): improved motivation
	<i>Drinking to deal with daily life and general life problems</i>	For example: needing to drink just to carry out simple tasks
	<i>Goals and desires for daily life functioning</i>	For example: improved motivation, be more productive, be more disciplined

4.3.1 Theme 1. Mental health and emotional wellbeing

“I was stressed out, I was an emotional wreck, and I couldn't handle life” (Hannah)

The first theme identified in the phase one interview data relating to the participants’ meaning and experience of QoL was mental health and emotional wellbeing. Participants

gave a lot of weight and significance to the theme of mental health and emotional wellbeing concerning their meaning of QoL. They had considerable awareness about their mental health and emotional wellbeing and had undergone struggles within their experiences of QoL concerning mental health and emotional wellbeing and PAU. The subthemes identified within this theme, and presented in individual sub-sections below, were:

- The adverse effects of alcohol use on mental health and emotional wellbeing
- Drinking alcohol to improve mental health and emotional wellbeing
- Consequences of recovery from PAU for mental health and emotional wellbeing
- Goals and desires for mental health and emotional wellbeing

4.3.1.1 The adverse effects of alcohol use on mental health and emotional wellbeing.

Many participants spoke about their QoL experiences and perceptions of the adverse outcomes of alcohol use on their mental health and emotional wellbeing. For these participants, drinking behaviours seemed to have a negative impact on their QoL. For example, respondents spoke about the negative impact of PAU on their mood, emotions or thinking. Daniel spoke about how he had depression and how he felt that “alcohol makes it worse”. Jack talked about how depression was always there in his head and how he got depressed when he was drinking, and that alcohol didn’t take away his depression. Grace also spoke about how alcohol made her depression “worse”. Chloe described how she had “been in a few psychiatric wards “due to her “extremely low mood after bingeing”. Mark described how alcohol negatively impacted his mood and thinking in that “the next day after a heavy night bingeing you’d have the fear, be re-thinking everything”. Many interviewees described experiencing feelings of shame, guilt, or embarrassment because of PAU. For example, Chloe talked about how she felt shame and how her “self-esteem was through the roof” when she was drinking, but then she would “come down afterwards” and feel “the regret, the guilt,

the shame”. Luke described how being “content or happy is waking up in the mornings now without that hangover, without that anxiety”. Emily spoke about the impact of her PAU on her children and described how bad she felt for her children and the “guilt, [she had] been carrying around for years”.

Most of the interviewees described feeling regret due to PAU. For example, Tracy described feeling regret over things she should not have done or said when she was drinking, and this would negatively affect everything in her life:

The next day then you’ve the ‘fear’ and you’re regretting things, like...what you shouldn’t have done or what you shouldn’t have said...and then not feeling good about yourself...It just affects everything.

Several participants described hitting an all-time low or a 'rock bottom' in their mental health or emotional wellbeing due to PAU. For instance, Hannah described how she felt “a lot more full” in herself now that she was in recovery but that when she was at her rock bottom in her addiction to alcohol she “was nothing then”. Adam described how his addictions to alcohol and drugs led him to suffer psychotic episodes, which resulted in an attempt at ending his own life. Other participants also spoke about the potential for suicide or self-harm due to PAU. For example, Grace described how she had “wanted to take her own life” after she had been unfaithful to her partner when she was drunk. Interviewees described experiencing mental or emotional comedowns from alcohol. Tracy described the “aftereffects” of alcohol on her mental health and how they were “horrible” and “scary”.

Luke also described the horrible place he would be in when waking up after drinking.

I know what it's like to wake up and look at that fucking ceiling and then [for it to] slowly dawn on you “oh fucking hell”...I know what that feeling is and it's a horrible place and I know drink brought me there.

Participants also described the negative impact of PAU on their self-esteem, self-belief, self-worth, or self-confidence. For instance, Conor described how alcohol made him “feel really bad” about himself and made him “lose all confidence”. He also talked about how low his self-esteem and confidence were when he drank, but that when he stopped drinking he was a “different person” and could “look you in the eye”. Chloe described her negative “self-talk” due to her PAU.

Even if I had the best of intentions of doing something, I'll talk myself out of it because my self-talk is, ‘You're useless. You can't do anything...’ That person hates you because... God knows what you said to them when you were drinking.

Many participants described experiencing anxiety, fear, worry, or panic due to PAU. Daniel talked about having anxiety and how he “wasn’t helping” himself around it because alcohol “makes it worse”. Tadhg described how not hearing from others would make him feel worried that they “didn’t approve” of his alcohol use and what he’d been doing. Chloe described that even a month after drinking she could still have anxiety and “the fear”.

Participants also described a negative outlook towards the world, which may have resulted from their drinking behaviours and the problems they caused them. For instance, when Grace was asked to describe how a positive day might turn out for her, she said “I can't think of a good day”, and instead, she emphasised how a typical day, or “every day”, was a bad day for her. Daniel seemed discouraged when he described the issues around getting to see his children due to his PAU. He described how it was “stressful not having access” to them and felt that they “don’t really wanna [sic] know anything about me”. Some interviewees described feeling confused or lost due to PAU. For instance, Emily described how she would question herself as to why she kept repeating behaviours and how she would “look at the pictures of my kids on the locker [and ask herself], why are you doing this?” but then she

would wake up the next day and “need another little bit” of alcohol. Hannah described how she felt that she was losing herself and her soul due to PAU.

I had become someone that I didn't recognise. I was losing myself. I was losing my soul. All my morals, my sense of right and wrong; anything that meant anything to me in my life, they were all gone. All that mattered was getting more drink.

Hannah described how alcohol “destroyed everything” and led to her feeling “empty and meaningless”. She also described how alcohol changed her into a “shell of a person”. She felt that alcohol had made her into a “completely different person...like a down and out, who cared about nobody”. Some of the respondents described experiencing anger or frustration due to PAU. Adam described how unsatisfied he was with life when he was drinking because he was “so angry” and “not happy at all”. Emily described how she was “a different person with drink” and how she could get “abusive to her husband” when she was drinking. Chloe described the frustration and anger she felt towards her family and how she didn’t want them “disturbing” her or telling her she is “not supposed to be doing it” and how she would feel like telling them, “leave me alone and let me have my drink!!”. A couple of participants described feeling hopeless or trapped due to PAU. Robert described how, over time, he felt that he had become “trapped” by alcohol. Finally, Chloe described how her alcohol use brought her to the hopeless point of thinking “I don’t want to be here anymore” and “I can't do this anymore”, and led her to wonder “what's the point?” of doing anything in life.

4.3.1.2 Drinking alcohol to improve mental health and emotional wellbeing.

Many interviewees spoke about their QoL experiences and perceptions of drinking alcohol to improve their mental health and emotional wellbeing. For these participants, drinking behaviours seemed to enable them to experience improvements in their QoL. Respondents talked about drinking to escape, to forget past experiences (e.g., traumas), to

relieve their thinking, deal with issues, or to numb out or escape from “real life”. For example, Bernadette spoke about how she would drink herself “senseless”. Jack also revealed that he drank alcohol as it “blocks the mind”. Chloe talked about how she never drank for fun and drank “as quickly as possible” to get “obliterated” as she “didn't want to think anymore”, she “didn't want to feel”, and she just wanted to “pass out to pass the time”. Liam described how he drank because he wanted to get “out of his head” (i.e., escaping his thoughts through drinking behaviours) as his head was his “worst enemy”. Nearly all of the respondents spoke about trauma in their lives and how they would drink to help them deal with the trauma. Bernadette spoke about the trauma of the untimely death of her adult daughter six years previously and its association with her PAU. She described how “reality without her is just hard” and that when she drank, she would “try and be happy” but would inevitably get “really upset over her” and “end up crying” over the untimely loss of her daughter. Jack told the traumatic story of losing his infant sister when he was eight years old and how he “started drinking a lot” then to help deal with the pain of it.

I was in hospital, like, for six months with her..... She had a hole in her heart and was feeding her with a syringe and all...I remember everything... The day, like, I got the phone call in school [...] [Name removed] told me what happened, I jumped out of the car, and I legged it into the house...found her...she was in the house...in a little, small white box... [It] broke me heart [sic].

Luke talked about the trauma experienced from working his job in the emergency response and how he would drink to help him deal with it.

I was drinking at night... because I'd have trouble sleeping and I think a lot of that is because of the experiences I've had... through the job...People would be... Familiar with from newspapers about incidents that happened over the years in Dublin....

Stuff that I would have been directly involved in... You know, ya play the macho game man, ya know...everything's sort of kept in

Most of the interviewees described how drinking helped them to cope or deal with stress, pressure, or boredom. Emily revealed how she “turned to drink for everything” and “for all comforts” after taking on too much of life’s stresses, especially around her family. Hannah talked about her “monstrous” levels of stress in life and how alcohol helped her to feel some relief from it.

So, anything I do, whether it's work, or college, I feel like I have to... Again, the worry of it, and the pressure of it, and the stress of it... Everybody deals with work pressures, and college pressures [but], like, my levels of that, are monstrous. So, everything is just in extremes. And it’s hard to manage...Like, if I had a glass of vodka, or a glass of whiskey right now...Ohh [sigh of relief]. It just gives me that sense of... [sighs again], “yeah, I can breathe now”.

Participants also talked about drinking to deal with negative feelings or emotions, to help their depression or low mood, or to fill a void within them. Conor described how he drank to “try to numb the pain”. Grace spoke about how drinking “helped my depression as well because you're just going out...forgetting all the stuff... getting drunk”. Tadhg described how alcohol “cancels out all your feelings” and that it “hides a lot of your problems”.

Participants spoke about drinking because of feeling unhappy, discontent, uncomfortable, empty, or feeling a 'void'. Tracy talked about how she wanted to “get a grip” on her alcohol use and “put a few things in place” around self-care for herself that would “fulfil something in that void” so she would not want to go out at the weekend and “get messed up or get drunk”.

Many interviewees also spoke about drinking to deal with anxieties, fears, worry, or panic. For instance, Tadhg spoke about how he thought one of the reasons he drank was because he

“suffered with an awful lot of anxiety”, and he was drinking to “balance this out”. Liam talked about how his anxiety would improve or get worse, depending on whether he had access to alcohol or not:

I’d get to the [automatic teller machine] and go ‘Ah, jaysus [sic], there is money there’. The anxiety... anxiety would decrease very slightly” “got enough beers to do me for the day...without even drinking one of them, having them in the car with me, sort of...the anxiety would subside.

Interviewees also spoke about how drinking alcohol helped them with self-confidence, self-belief, self-consciousness, self-esteem, or self-worth. For instance, Emily talked about how she was “lacking” in confidence and how she drank because alcohol gave her a “boost of confidence”. Tracy described the “buzz” she got from alcohol and how it made her “feel confident” and not worry or care as much about her problems. Some respondents spoke about how they drank to help deal with the symptoms of obsessive compulsive disorder (OCD). For instance, Robert spoke about how his OCD might cause him to feel stress and then if the “slightest little thing” went wrong, he would be “looking for a drink”. Finally, concerning drinking alcohol to improve poor mental health and emotional wellbeing, Tracy spoke about how she believed that people potentially drank to relieve feelings of loneliness, isolation, regret and shame.

4.3.1.3 Consequences of Recovery for Mental Health and Emotional Wellbeing.

Many interviewees talked about their QoL experiences and perceptions of the consequences of recovery or sobriety from PAU for their mental health and emotional wellbeing. Some participants described the benefits of recovery or sobriety on their QoL concerning their mental health and emotional wellbeing.

Interviewees spoke about happiness, acceptance, contentment, gratitude, enjoying life, or having a more optimistic or laid-back outlook, while in recovery. For instance, Robert spoke about his sobriety and how he was in a more “relaxed state” where “things aren’t getting me down as much”. Bernadette talked about how treatment opened her eyes and made her “realise there was people worse off” than her and that she “was just as bad as them as well” and that she needed help. Mark spoke about elements of his life that he was now “enjoying” while in recovery, such as exercising or connecting with family and friends. Hannah talked about gratitude in recovery and how everything in her life was now “wonderful” and how she now counted her blessings for the “opportunity to get better” and that she wouldn’t swap her life for anyone else’s. Participants also described being able to express themselves and open up more to others in recovery. Emily talked about how she was able to “open up” to others in treatment about issues related to alcohol and her recovery journey. Mark talked about how he felt a weight lifted off him as treatment helped get things “out of your body” and described the benefits of getting “feedback off people who know what they’re talking about”. A few of the interviewees described experiencing more positive feelings and emotions in recovery. Luke talked about how he was feeling better in himself and talked about the “benefits to [his] body and mind from not drinking”. Emily described her perfect day as a sober day and how good she would feel at the end of the day for not drinking.

My perfect day is... getting me kids, and maybe go for a walk to the shop [sic]. I love going home in the evening times and I love knowing that I’m getting into bed and, my daughter’s in for the hugs...I love that...[thinking] ‘you’ve got through this day, again, without drink’

Respondents spoke about improved self-care, self-worth, self-belief, self-esteem and self-confidence in recovery. Hannah talked about self-care and setting boundaries in recovery

and learning “to say no to things” and accepting what she can take on and what she cannot. Tadhg illustrated how his confidence was growing and that he could lift his head up and say “I’m doing ok” since he had been going to treatment. As well as the positive aspects of recovery, some participants spoke about their experiences and perceptions of the negatives of recovery from PAU for their mental health and emotional wellbeing. For these participants, recovery from drinking behaviours may have resulted in a negative impact on their QoL. Hannah talked about how challenging it was “learning how to live with the way I feel things, without anything at all to numb it”. Luke talked about how a combination of no alcohol and being away from family on one's own with one's thoughts can leave one feeling mentally “shaky” and “vulnerable”. Tadhg spoke about how he was still feeling very raw in his early stages of recovery and, as a result, felt less satisfied with life. When describing how satisfied he was with his life in early sobriety, he described it as a three out of ten and described how recovery was “still very raw”.

4.3.1.4 Goals and Desires for Mental Health and Emotional Wellbeing.

Participants talked about their goals or desires for their QoL concerning their mental health and emotional wellbeing. Many of the participants highlighted the importance of self-care and taking time for themselves, which also included getting recovery for themselves rather than doing it for other people. Daniel spoke about how he was putting off looking for a job now in sobriety as he needed “the time out now” to “rehabilitate” himself. Adam spoke about how he positively replaced his “addiction to drink and drugs to an addiction to food” and how he now loved “the satisfaction of sitting down after you've prepared and cooked” a meal. When describing what happiness was to him, Conor spoke about “being able to take time out and say, ‘Look, I deserve to have this hour to myself now’”. Several respondents spoke about their goals or desire for better moods, feelings, or emotional health. For instance, Tadhg

talked about how he believed that he generally felt sad more than others, but that he wanted to improve this in recovery:

I would get the sad thoughts and - more than, you know, the ordinary joe soap in the street - my goal is to sort of get rid of all that...And, I think walking would help, and picking up sport or something...snooker, whatever. Just to get myself back together

Participants also spoke about their goals for contentment, peace, gratitude, and feeling whole in recovery. For instance, Daniel spoke about his goals to get into the space where he would be relaxed and content and happy with his life so he could then “get back doing a few bits of activities and engage with people”.

Participants spoke about their goals and desires to improve their confidence, self-care, and self-acceptance in recovery. Chloe described her plans for her life in recovery, how she planned to “look after” herself and how in recovery she would know who she was and be “able to be that person”. Chloe also spoke about how she felt that, if she got a period of sobriety behind her, she would get confidence in herself and know that “no matter what comes along I'm strong enough to be able to deal with it without reaching for a drink”. Daniel talked about not wanting to “worry about anything” anymore and wanting to “be happy with myself” and “start looking after myself”. Participants spoke about how they would like to engage in practices like meditation and mindfulness for their mental health and emotional wellbeing. Hannah described how she would like to see herself “as somebody who regularly does yoga, who regularly meditates, and is just at peace with themselves”. Interviewees spoke about how they wanted to have more positive attitude and outlook and be more relaxed with life and themselves. For instance, Liam talked about how getting some “positivity back in [his] head” might help him in his journey to recovery from PAU, but that this was difficult as he did not have the positivity, he felt he needed, to do something about it. Chloe described how she wanted to have a more laid back outlook as “just being able to go with the flow”

would mean good QoL. Participants spoke about how they still wanted to escape, numb out or forget things without alcohol. For example, Grace talked about her goal to find alternatives to alcohol to help her “forget about stuff”.

As identified in the data, mental health and emotional wellbeing were significant to participants' meaning of quality of life as they lived through and were living through much mental health and emotional wellbeing experiences related to their QoL and PAU. The next theme identified in the data from phase one was social connectedness.

4.3.2 Theme 2. Social Connectedness

“For me it was around loneliness...I found it very hard to make contact with people.”(Emily)

Another central theme identified in the interview data concerning participants' meaning and experiences of QoL was social connectedness. Participants highlighted the significance of relationships concerning their QoL and realised the implications of PAU for their relationships and QoL. Subthemes identified in this theme, and presented in individual sub-sections below, were:

- Negative impact of PAU on relationships
- Drinking alcohol to connect with others or to alleviate social disconnection
- Connecting or reconnecting with others due to recovery from PAU
- Losing connection with others due to recovery from PAU
- Goals and desires for relationships and connection to others

4.3.2.1 Negative impact of PAU on social connectedness. A subtheme

identified within the theme of social connection was the negative impact of PAU on relationships. For these participants, alcohol use had a negative impact on their relationships and subsequently their QoL. For instance, participants spoke about social disconnection due to PAU. Many interviewees talked about conflict, confrontation, friction or discord within their relationships due to PAU. For example, Chloe spoke about how she felt “disconnected” and “on the outskirts” from her family, how they pushed her away due to her PAU. She also talked about how it would be “massive” for her to reconnect with them, especially with one of her sisters who had just had a baby. Jack talked about how he realised that alcohol was a problem when he “started fighting” with his girlfriend. He also spoke about how his

girlfriend gave him an ultimatum to choose between "the drink or the kids". Grace talked about how she "messed up" by being unfaithful to her partner on a night out when she was drunk and how she "ruined" the relationships. She spoke about how this made her feel more depressed and made her doubt everything about the relationship with her partner. Mark spoke about how alcohol caused him to have "a lot of family problems" and "have a lot of problems at home" through "arguing with [his] mam". Robert spoke about how alcohol "just took everything away" including his relationships and how he fell out with people due to PAU. Respondents spoke about isolation, seclusion, being avoided, or difficulties dealing with, or engaging with, others due to PAU. Bernadette described an image of unhappiness as drinking herself "senseless", while "none of your family want to talk to you [...] no one's given ye the time-of-day. [...] People snub you and look you up and down". Conor talked about how drink made him "feel really bad" about himself and how he would "lose all confidence" and "find it hard to deal with people". Mark talked about how he "distanced" himself from close friends due to his drinking. Interviewees spoke about being dishonest, keeping secrets about their drinking or manipulating others due to PAU. Chloe talked about the "pressure" and how "exhausting and draining" it was to pretend to her parents and her counsellor that everything was great and perfect all the time when it was not due to her alcohol use. This fear of being judged made her feel like she was not "good enough". Grace also spoke about how she would not open up to anyone about her PAU, and how she would lie to her counsellor about it. Some respondents expressed a lack of motivation or engagement within their relationships due to PAU. Emily spoke about how she didn't go out to social events anymore and avoided situations that involved alcohol, and how she had now "lost loads of friends" due to her issues around alcohol and giving it up. Some of the participants talked about feeling judged by others around them, or they worried about being judged by others due to PAU. For instance, Chloe spoke about how she would presume people hated her based on what she may

have said to them when she was drunk. Conor spoke about how, at times, he would feel “judged” by staff working in treatment or housing services and how he thought they were thinking, ““you’re here and you should be grateful””. A couple of respondents spoke about how they would defy or ignore others when they were drinking. Chloe talked about how, when she was in the “height of her drinking”, she did not want anyone “disturbing” her and just wanted people to leave her alone and let her have a drink. Many participants spoke about how their PAU had a negative impact on those around them. For instance, participants spoke about how their PAU worried others or made them fearful. Emily described the impact her PAU had on her children and “that fear in their faces, if I had a drink”. Hannah spoke about the worry and fear her PAU brought to her mother and grandmother and how her grandmother described her as the “biggest worry” in her life. A few of the participants spoke about how unreliable they were, how they could let others down, or how they could upset or disappoint others due to their drinking. For instance, Chloe talked about how alcohol took away all the things she valued about herself, including her reliability, as she would “commit to plenty of things” when she was drinking but then would “never show up”. Tracy described how she could miss getting her children ready for school because she would have a hangover. Liam talked about his “really close friends” and how, because of his alcohol use, he had “hurt” or “disappointed” them. Hannah described how she would cancel plans to see others if she was having a bad day:

As soon as you wake up, [you have] this feeling of “Ugh...Oh my God, I just can't be dealing with today”. If I had arranged to see my brothers and sisters, or my Mam and Dad, or Grandparents or something, that would all be called off, because I feel that I can't be around my family.

Participants spoke about becoming violent or aggressive towards others when they were drinking. Daniel talked about how he realised drinking was a problem for him when he

started fighting with others and “getting arrested for being drunk and disorderly”. Mark spoke about times when he was drunk when he was “very aggressive and out of order”. Hannah spoke about a time when she screamed at and attacked her mother “like some kind of crazed animal” when she was drunk. Participants also spoke about how they could be unreasonable or unfair to others, or how they could abuse others’ trust, due to their alcohol use. For example, Hannah spoke about how she abused her grandmother’s trust by giving her Valium to make her sleep so she could go to the pub and then stole €100 from her purse for alcohol, justifying it by believing that her grandmother would have given it to her either way. Bernadette described how she could be unreasonable to her husband as she would “throw” him out of the house so she could be “on her own to drink” and that he would then be “walking the streets” with “nowhere to go”. When she would stop drinking, she would realise she was in the wrong and call him back to apologise. A few of the participants talked about their alcohol behaviour and how it could embarrass others or make them feel uncomfortable. For example, Emily described how her family would “dread” it if she was drinking when they would go out together.

4.3.2.2 Drinking alcohol to connect with others or to alleviate social

disconnection. Many participants spoke about their experiences and perceptions of drinking alcohol to connect with others or to alleviate social disconnection. For instance, all participants talked about drinking to socialise, to have a social life, to have fun, to connect with others, to alleviate social pressure and the drinking culture in Ireland and the normalisation of drinking. For these participants, drinking for these reasons seemed to have both a positive and negative impact on their QoL. Bernadette spoke about how she had relapsed and gone “back on the drink just to socialise”, but that she was only “fooling” herself with this, and she ended up hitting the alcohol “with a bang”. Grace spoke about how

her drinking was “mainly socially”, but that she would still end up blacking out “every time I went out, which could have been every month or so...maybe more sometimes”. Tracy described how she was always “a binge drinker” and “a party person” and how she would “live for the weekend”. Robert described how his drinking started off as a “weekend thing” and “meeting the lads after work for a pint, kind of thing” and how everybody he knew drank but that it eventually crept up on him without him “realizing it or knowing it”. Luke described how his life “revolved around the social scene” and everything was “pub related or drink related or party related”. Liam spoke about his early days of drinking and how “it was all social drinking”, while Conor spoke about how he had to avoid socialising with people who were actively drinking to stay sober. Many of the participants highlighted Ireland’s drinking culture and the normalisation of drinking alcohol when socialising or connecting with others. For example, Mark spoke about how he still wanted to “control it [his alcohol consumption] and still go out and have it” because “everyone likes to go out and have a good time and have a few drinks here and there”. Luke spoke about his career in the Irish army and how it was dominated by a culture of alcohol and drinking with other soldiers.

I joined the army as a young fella. [...] I was just constantly drinking, you know? [...] Literally everybody was doing it, you know? 600/700 fellas on a tour of Lebanon; anybody who wasn't on duty, the rest was in the bar [sic].

Many interviewees talked about drinking to alleviate isolation, loneliness or to help with their difficulties connecting or interacting with others. Tracy spoke about how she would sit with herself for too long and forget about the outside world, which would lead to her wanting to drink and meet people.

The thing is [that, if] I sit with myself for too long, what happens is [that] I forget about the outside world... You get drink and then you go out and you meet people and you're having a laugh...it's kind of a buzz [fun].

Bernadette spoke about her loneliness and how alcohol could alleviate this by giving her the confidence to connect with others.

For me, it was around confidence, loneliness...I found it very hard to make contact with people. With the few drinks on me, the first thing I'd do was make that phone call...I could be on the phone for an hour.

Most respondents spoke about drinking due to relationship issues, such as dysfunctional relationships, relationship break-ups, or the death of a loved one, or someone close to them.

Tracy talked about the “void” and “hurt” after a relationship break-up and how she was drinking more as a result of it. Adam spoke about turning back to drink and drugs after the reality of his brother's death from suicide suddenly “hit” him. Daniel spoke about how issues around his relationship with his daughter contributed to his PAU.

My daughter had four kids so... She became a heroin addict when she was very young...I got her into counselling two or three times and she relapsed then, and so the family unit broke down. So...that caused a lot of stress and that's caused me then to relapse then on the drink...

A couple of participants talked about drinking due to feeling hurt, insulted, criticised or disrespected by others. For instance, Robert described how, if somebody said something to him that put him in a bad humour, he might then look for a drink.

If somebody said something, even something funny to me, or even somebody I didn't know in the street, they could just put me in a kind of a bad humour [and] I'd be [saying to myself], like, just, "ahh, get me a drink!"

Conor described how he felt unsupported and how “there was nobody there” to give him the support he needed in treatment which he then said gave him “the green light” to “go off and have a drink”.

4.3.2.3 Consequences of Recovery or Sobriety for Social Connectedness.

Many participants spoke about connecting or reconnecting with others due to recovery from PAU, which was another subtheme identified within the primary theme of social connection. For these participants, connecting or reconnecting with others seemed to have a positive impact on their QoL. Many participants talked about experiencing more honesty in their relationships, more openness, and more positive connection and interaction with others due to recovery. For instance, Chloe spoke about how her family had “a lot of time” for her since she had started a recovery programme, and how her mother now rang her every day. She also felt that they would help her now if she “needed anything”. Conor spoke about how “normality” to him, when he was clean and sober, was “finding time to meet people” and “having fun with loved ones”. Many interviewees spoke about making amends or having compassion towards others while in recovery from PAU. Conor talked about how he just wanted to get his life back and try and help other people following PAU. He said that he just wanted to “live a happy life” and hoped to “help someone else instead of going around bleedin’ annoying people [sic]”. Bernadette described how connecting with her granddaughter, while in recovery, made her feel that she had a second chance at life and her relationships with her family.

Being around my grandchild made me realise -she makes me realise what I missed out on with my own kids... Being a grandmother, it's like a second chance, ye know? What you couldn't do with your own kids, you do with your grandchildren and...try to put things right.

A couple of participants talked about taking influence and advice and learning from others in their recovery. Grace described a particularly low moment in her life due to PAU and how it led to her connecting with family and telling her aunties “everything” about her alcohol use.

A few participants spoke about how they could still socialise and connect with others even though they weren't drinking. For instance, Daniel spoke about how he didn't "have a problem going out socialising with [his] friends... if they [went] to the pub or out for a night out or a party" and described it as "not a major issue". Adam described how he could still go to his local pub and "have a bit of craic without drinking". In contrast to the above, other participants identified how they lost connection with others due to sobriety or recovery from PAU. For these participants, losing connection with others due to being sober or in recovery seemed to have a negative impact on their QoL. Some respondents spoke about avoiding others, and therefore losing social connection with others, due to not drinking. For instance, Hannah talked about how she "didn't want to be going out", so she "stopped going out" and "stopped seeing friends" after she stopped drinking. Emily also spoke about how she "lost loads of friends the last two or three years because of drink and given up, and not going out". Some interviewees also spoke about the fear of social connection or the fear of losing social connection due to not drinking. For example, Emily talked about how "it was always a nightmare because I wasn't drinking" and how she was "absolutely dreading" a family wedding in Portugal because she was not going to be drinking.

4.3.2.4 Goals and desires for relationships and connection to others. Most of the participants talked about their goals and desires for relationships and connection to others in recovery. Participants spoke about their goals for making amends, improving relationships and having better connection with others. For instance, some of the interviewees wanted to connect or reconnect with family, friends, or loved ones. Chloe spoke about how her life had not "really changed" in recovery as she was still "not really in touch" with her family but she wanted to work on this. Luke talked about how, when he was younger, he would read to his

wife in bed, and how much it would mean if he was to do this again. This goal seemed especially important due to the trouble he and his wife were going through due to PAU.

I used to read to her in bed. I'd read a book. [...] I'd love to read that book again, man... You asked "what would make me happy?" That would make me happy. For that to happen would mean so many things have found a place. If I was to lie there and read a book, you know, before bed and read a few chapters and she'd listen to the book. That would speak volumes about everything else...

Several participants also spoke about how they wanted to have more open communication within their relationships with others. Conor talked about the difficulty he had in telling people what he had done in his life while drinking. He said that, if he were to open up and tell someone, he would have to find someone he could "trust". A few participants spoke about how they did not want to impact others negatively and instead wanted to make others happy following their recovery. For instance, Emily talked about how she did not want her children to "smell drink" off her, to see her "slur" her words, or to "be afraid" of her. Bernadette spoke about why she wanted to get her life back on track for her children, grandchildren, and herself:

It's time I'm getting my life together... Getting me life back on track because I have grandkids and children and I have to do it for them, if I'm not doing it for meself [sic] ...most of all I have to do it for myself...cos I'm only 45 and I don't want to...just go yet, ye know?

Some participants spoke about how they hoped to get more support in recovery. Jack spoke about how he needed to continue to "talk to people" in the community treatment centre to improve his satisfaction with life. Tadhg spoke about how he wanted to get someone to "help control [his] emotions". Bernadette talked about how she was looking forward to getting support when she entered residential treatment and hoped she would have that same support

after treatment. Participants spoke about how they wanted to have compassion or wanted to help others. Tracy spoke about how she “used to be a carer and used to love helping people” and thought about getting “back into doing something for the community and helping people”. Conor spoke about how he wanted to “give back” to others and how he would “be happy... if I help somebody”. Some participants spoke about how they wanted, or needed, respite from relationships. For instance, Liam spoke about a recent admission to hospital and how it was a relief for him as it gave him a break from caring for his partner and all the responsibilities that went along with being “tied then to someone else's regime”. Some participants spoke about their goals or desires around getting acceptance from others or getting approval or validation from others. For example, Tadhg described how happiness for him included people validating him:

That would be happiness for me, you know, feeling good about myself and, I suppose if I do a bit of work, and things work out good for me, I'd be happy that way...people saying nice things to me, you know, ‘You did a great job’”.

Hannah spoke about a past relationship and how she felt that if her ex-partner “just loved her”, things would be better for her now.

The above findings on social connectedness show how meaningful relationships were for participants concerning QoL, how behaviours around alcohol use negatively impacted these relationships and how participants drank alcohol to improve their social QoL. The next theme identified in the data was physical health.

4.3.3 Theme 3. Physical Health

“The shake of the hands. You know what I mean? Not being able to control it.”(Tadhg)

Another primary theme identified in the interview data concerning participants' meaning and experiences of QoL was physical health. Participants' perceptions were that physical health was a factor within their QoL, and their experiences concerning PAU included alcohol harming their physical health and drinking alcohol to relieve physical discomfort. The subthemes identified within this theme, and presented in individual sub-sections below, were:

- Negative physical outcomes of PAU
- Drinking alcohol to ease physical discomfort
- Physical benefits of recovery from PAU
- Goals and Desires for Physical Health

4.3.3.1 Negative physical outcomes of PAU.

Many respondents talked about the negative physical outcomes of PAU. Most respondents spoke in general about the negative physical impact of PAU. For these participants, the negative impact of PAU on their physical health had negative implications for their QoL. For example, Jack spoke about how alcohol had “fucked” his liver. Bernadette described how her general health was “gone to bits from the drink”, how she had cirrhosis of the liver, and how if she didn’t give up she would be “dead in 12 months”. Robert spoke about how he was in “hospital a few times” with what he thought were heart attacks but which were panic attacks and how he “used to get pains in [his] body” due to his alcohol use. Tadhg spoke about how he was “taken to the hospital” a “few times [...] because of ulcers” in his stomach due to his alcohol use. Participants also spoke about physically hurting themselves due to being drunk. For instance, Grace told about how she hurt herself and was “clumsy” when drinking and that she had previously "smashed her face" when she was drunk. Adam spoke about how he fell down the stairs and broke his collarbone after drinking and “sniffing coke”. A few participants also spoke about neglecting

their personal hygiene due to alcohol use. For instance, Chloe spoke about how her “personal hygiene was gone” due to her PAU and that she wouldn't shower or brush her teeth “for weeks”. Mark also told how he “wouldn't even have been brushing [his] teeth every day [and] only showering every 4 or 5 days” when he was actively drinking. Many participants also spoke about becoming too drunk or having blackouts from drinking. For instance, Tracy talked about how “you don't even remember getting home the next day” as she would binge on alcohol and blackout. She also talked about how she might fall during one of these blackouts. Emily spoke about how she asked her doctor why she had blackouts and how she would always “be the one that would fall”. Bernadette spoke about “taking blackouts all the time and not remembering nothing” due to her alcohol use. Grace spoke about how she started to take cocaine to help stop her “drinking until blackout”. Many of the interviewees spoke about physical alcohol withdrawal or hangovers. Liam talked about his “withdrawals” and how he “collapsed”, “got a seizure”, and ended up in the hospital because he “cold turkeyed it [sic]” and stopped drinking alcohol suddenly with no medical support. When Adam and Emily were asked to paint a picture of being unhappy, both described this as being hungover. Luke spoke about “the sickness [and] the feeling of nausea” after “coming off a nights drink”. Some participants also spoke about sleep issues as a result of PAU. For example, Conor spoke about how he found it “very difficult to sleep” when he was drinking as his mind would be in “turmoil”. Chloe also talked about how hard it was for her to sleep after an alcohol binge and that it would take “at least a week to be able to have a full night's sleep without lying there awake or waking up every few hours”. Mark described how he would “stay up all hours” and not get a “proper sleep” and therefore his “mood is really effected”. Finally, in relation to the subtheme of negative physical outcomes of PAU, several participants spoke about not eating well due to their alcohol use. For instance, Mark talked about “eating rubbish or just going a day or two without [food]” when he was on a drinking

session, and that he would also eat poorly in the days that followed. Robert described how in sobriety he was “eating a whole lot now” and it was “better than what [he] was eating before”. Luke described how his “appetite was terrible” when he was drinking.

4.3.3.2 Drinking Alcohol to Ease Physical Discomfort.

Nearly all of the participants spoke about drinking alcohol to ease physical discomfort. In this way, participants perceived that their alcohol use had a positive impact on their QoL. Many participants talked about drinking to alleviate their physical cravings or urges. Adam spoke about his cravings and how he would be sitting at home “watching the clock for the pub to open”. He also described how powerful his cravings were and how they would dominate his thinking. A couple of participants spoke about how they were drinking due to the physical need for alcohol. Hannah talked how alcohol became something that she “absolutely had to have” and described her need for alcohol as a “physical need, like needing water”. A few participants described drinking to help with their hangovers or alcohol withdrawal. Hannah described her experience of a morning when her hangover was so bad that she brought alcohol to work with her.

One morning I woke up and, dying of a hangover, knew I was going to start puking and shaking, and [that I] wouldn't be able to go to [work]. But, the only thing that would get me through is if I had another drink...I went outside to have a cigarette, and was taking sips from this water bottle of red wine because it was the only way that I could have made it through that day.

Robert also spoke about how he started drinking in the mornings due to his hangovers and would say to himself, “Have a can, it'll make your better”. Interviewees also spoke about drinking to help them sleep. For instance, Luke talked about how he found it hard to sleep and how he “was drinking at night... because I'd have trouble sleeping”. Robert spoke about

how he would drink to relieve physical pain. He said he would get physical “pains” in his body so he would drink to “kill that pain”.

4.3.3.3 Physical benefits of recovery from PAU.

Nearly all of the respondents spoke about the ‘physical benefits of recovery from PAU’. Respondents also talked about looking after their physical health more, exercising more, and their physical health improving in recovery. Bernadette highlighted the importance of giving up alcohol for her QoL and how it was a priority now for her to give it up so that she could get her “health back” and her “life back”. Mark talked about how he needed to stay away from drinking heavily to keep his health in check and described the fears he still had around his health due to his previous addictive behaviours.

[When I] get to thinking of what’s going to happen in the future, [I’m] scared [about what would happen] if I take cocaine again... So, I was down in the doctors a few days ago, after I had the seizure, and she said that, if I were to drink that much and take cocaine, I could risk that another seizure could happen.

Tadhg spoke about how, when drinking, he would “stay in bed for a long time, like a few days”, but, now that he was in recovery, he was choosing more positive activities, such as getting up and going for walks. Luke talked about his recovery from PAU and how he was now “feeling good” in his health and appearance, and how he could now see the benefits to his body and mind. Daniel spoke about how he noticed in recovery that his physical health was improving and that he was engaging in more physical activity.

I started doing these (inaudible) and cross-country runs and everything with all my work colleagues for days out, ye know, and so I did notice an improvement in my physical health.

Some of the respondents talked about their sleep improving due to recovery and not drinking. Conor talked about how, when sober, he could “hit the pillow” at 12, and then be awake very early the next morning with a “spring” in his step. Daniel described how he had started noticing in recovery that he was “able to wake up now” in the mornings after “getting a full 8 hours sleep”. Some of the interviewees spoke about eating well or having an improved diet due to recovery from PAU. Robert compared his current diet while in recovery to his diet back when he was drinking. He spoke about how he “had a very, very bad diet” and “wasn’t really eating at all” when he was drinking, but that his diet in recovery from PAU was now “a lot healthier”.

4.3.3.4 Goals and desires for physical health.

Participants talked about their goals or desires for their physical health, in particular around exercise and eating healthy. Tracy revealed that she wanted to “do a bit more stuff on self-care like meditation or yoga” so she could “fulfil” something in herself. Robert described how he was in the gym at half eight every morning and how his “plans for the future” were “keeping [him] strong”. Liam spoke about how he would “love to have [his] health back”. Emily spoke about her goals and how she wanted to “go back walking in the evening times with the dogs and stuff like that” rather than being in the house where she “could be drinking”. Daniel spoke about his plans for more exercise now that he was in recovery from PAU and how he was “getting the body back on track” to “try and build up to fitness”. Participants also spoke about their goals for improving their diet. For example, Robert talked about how he was “working a bit more” on his diet and was eating a lot healthier in recovery than when he was drinking and that he was now making more home-cooked meals rather than getting unhealthy takeaways. However, he still felt that he could “do a little bit better in that way”.

The theme physical health was identified in the data concerning the participants meaning and experience of QoL. Participants PAU had negative implications for their physical health and QoL while they also drank to ease physical discomfort to improve their QoL. They also highlighted the benefits of recovery for their physical health and their goals and desires for their physical health. The next theme that was identified in the data was altered daily life functioning.

4.3.4 Theme 4. Altered Daily Life Functioning

“I wouldn’t have the energy to get dressed.” (Bernadette)

Another primary theme identified in the interview data relating to the participants’ meaning and experience of QoL was altered daily life functioning. Participants spoke about how they functioned in day-to-day life in relation to their PAU and recognised daily functioning as an important aspect of QoL. Subthemes identified within this theme, and presented in individual sub-sections below, were:

- Drinking to deal with daily life and general life problems
- The negative impact of PAU on daily life functioning
- Daily life functioning and recovery from PAU
- Goals and desires for daily life functioning

4.3.4.1 Drinking to function and deal with daily life and general life problems.

Some participants talked about how they would try to improve their QoL by drinking to help deal with daily life and general life problems. For these participants, alcohol use seemed to have a positive influence on their QoL. For example, Tadhg described how he felt alcohol gave him a “cushion to lie on” to help him “get through life”. Chloe spoke about the times that she was “drinking to survive”. Emily described how at times she was “relying on the few drinks to even make a phone call”. Hannah described how, at times, drinking alcohol was “the only way that [she] could have made it through that day”. Tracy spoke about how she felt that she still drank alcohol because she felt she was stuck in a rut in her daily life.

I really don't know I just feel like I'm kind of stuck in a bit of a rut in me life [sic], ye know? And I think that's probably why I still drink. Because, I think, if I was a lot happier in me life [sic], I don't think drink would even come into the equation...

4.3.4.2 Negative impact of PAU on daily life functioning.

Participants spoke

about their experiences and perceptions of how PAU negatively impacted their daily life functioning. For these participants, alcohol use seemed to have a negative impact on their QoL. Participants spoke about how PAU had negative consequences for their lifestyle and their daily life in general. For example, Daniel described how “most of the problems stem from the drink”. Luke also stated that “99% of problems started with drink”. Conor described how “everything is just chaos” due to PAU, while Bernadette told how PAU “just wrecks everybody’s lives”. Tadhg spoke about how he had “destroyed [his] life” due to PAU, while Hannah told about a time in her life when alcohol had a hugely negative impact on her daily life. She described “living off noodles” because “all that mattered was drink.” and how she “literally had nothing”. Most participants described a lack of self-motivation around daily tasks, self-care and general daily life due to their problem drinking behaviours. For example, Robert talked about how he had “no energy” and “didn’t want to face the day” as he had “nothing to look forward to” when he was drinking. Emily spoke about how she generally took the time to “look after” herself and her appearance, but that this then changed due her behaviours around alcohol and how she would see herself “deteriorating” due to alcohol. Bernadette talked about how she “wouldn’t even shower” or sometimes even getting dressed and would “stay in my pyjamas” when she was drinking. Liam talked about how he felt that his PAU made him lose his motivation for life and how he “discontinued all the things I loved doing...the zest I used to have is more or less gone”. He also spoke about how he felt he always made the “wrong decision” and that he had not done much in his life, and he thought

this was due to “apathy” and alcohol being the “pinnacle of his thinking”. Tadhg talked about how, when he was drinking, a typical day might involve going “back to bed and [watching] television”. Several interviewees spoke about comparing their levels of motivation to the higher levels of motivation in others who had no issues with alcohol. This could result in feelings of jealousy. For example, Robert spoke about how he was jealous that his brother accomplished things in life, and that he could not, due to PAU.

My brother, we wouldn't get on because he's the opposite than what I am...

He's successful... He goes out and achieves what he wants and he barely drinks. I'd be kind of - it would be kind of like a jealousy thing... 'Why is he doing all that?' and 'Why can't I do it?'"

4.3.4.3 Daily life functioning and recovery from PAU.

Participants spoke about their experiences and perceptions of daily life functioning and recovery from PAU. For these participants, recovery from alcohol use seemed to have a positive impact on their daily life functioning and their QoL. Participants spoke about improved self-motivation within their daily lives due to recovery from PAU. For instance, participants talked about improvements around responsibility, self-care, discipline, routine, commitment, focus, or determination in their daily lives due to recovery from PAU. Tadhg spoke about how he was more motivated to complete his daily tasks and partake in valued activities since he had stopped taking alcohol and drugs.

Cleaning the car, hoovering the car.... I never would've thought of doing that over the past few years, you know? [I] just forgot about all that stuff, you know? It was more alcohol and drugs was more important to me at that time...I'm doing things that I haven't done a long time.

Robert highlighted his focus and determination by speaking about how he replaced his destructive drinking habits with a healthier lifestyle.

I had to change the habit. I had to replace it... I knew that, because I couldn't be sitting at home, [...] I got out and I got myself into the gym, and I'm up at six o'clock every morning...I've got plans for the future now.

Daniel talked about how he could “concentrate and do something” now that he was not drinking. Before he was in recovery, he would just sit around all day drinking, but now he could do chores such as cleaning the windows or the garden. Some interviewees spoke about engaging in healthier lifestyle activities now that they were trying to stop or cut down on alcohol use. Tracy described mindfulness and yoga as a self-care practice that she would not have typically been motivated to practice, but that she was now practicing every Monday as she wanted to “start doing things now for more self-care”. Tadhg also talked about how he was now engaging in more self-care practices, such as acupuncture, in recovery. He also talked about taking the time to focus on himself and his breathing when he was going to bed, which was helping him to sleep better.

4.3.4.4 Goals and desires for daily life functioning.

Participants spoke about their experiences and perceptions of daily life functioning and recovery from PAU. For these participants, recovery from alcohol use seemed to have a positive impact on their daily life functioning and their QoL. Many interviewees spoke about how they wanted to improve their daily life after PAU and learn to live without alcohol. Robert talked about how he wanted to improve his daily life and spoke of his “plans for the future”, which he felt were “coming together”. He said he was looking forward to them and he was not going to let alcohol “ruin that again”. He also spoke about how his plans were keeping him strong, how he was determined to stay in recovery, and how important having goals were as “you really

have to have something” to stay focused. He also talked about how he knew he had to “change the habit” of daily drinking and replace it with more positive and constructive everyday behaviours, such as going to the gym. Grace talked about her plans to “work” on herself in recovery and how she was keeping busy within her daily life doing a course in accountancy. Tracy talked about how she wanted to “get a grip” on her alcohol use and “put a few things in place” around self-care for herself that would “fulfil something in that void” so she would not want to go out at the weekend and “get messed up or get drunk”. Jack talked about how he needed to “cut down” on his daily alcohol intake and that to improve his daily functioning and his QoL, he needed to “get into detox and treatment”. Participants also spoke about their goals and desires for motivation in their daily life, particularly around their productivity, daily structure, their discipline, or their focus in life. Daniel spoke about how he wanted to learn how to “regulate and discipline” to avoid stress and relapse, or 'cracking' as he called it. Luke talked about how he wanted to “fine-tune” what he already had in his daily life in recovery so that he could get back some clarity, loving, trust, and enthusiasm in his daily life. Participants also revealed their goals and desires for their daily lives in terms of taking part in hobbies that did not involve alcohol. For example, Emily described how she needed “to spend more time with [...] friends again”, but “where it's not around drink”. Tadhg talked about how he felt that he could achieve happiness without alcohol and that he wanted to engage with more events or hobbies that did not involve alcohol. Interviewees also talked about their desires to drink alcohol in a more controlled manner. For instance, Mark spoke about how he felt he would be able to drink in a controlled manner if he could just get his cocaine problem under control.

I can control the alcohol without the cocaine. I think it's the cocaine that I'd really like to get out of the way completely. I'd like to go back to the way I was a few years ago

and go for a few casual pints and that's it. I don't know if that's going to be able to happen or not. So that's what the picture would look like really.

The fourth theme identified in the data in phase one was altered daily life functioning. Participants spoke about drinking to deal with their functioning in daily life and the negative impact of PAU on their daily life functioning. They also spoke about recovery concerning their daily life functioning and their goals and desires. The next and final theme identified in phase one was socio economic factors.

4.3.5 Theme 5: Socio-Economic Factors

“Now my money disappears.”(Chloe)

Another theme identified in the interview data concerning participants’ meaning and experience of QoL was socio-economic factors. Participants gave meaning to socio-economic factors as part of their QoL and described their experiences around socio-economic factors in relation to their alcohol use. Subthemes identified within this theme, and presented in individual sub-sections below, were:

- Negative outcomes of PAU on socioeconomic factors
- Benefits of recovery from PAU for socioeconomic factors
- Goals and desires for socioeconomic factors

4.3.5.1 Negative outcomes of PAU on socioeconomic factors. Participants spoke about the negative outcomes of PAU on socioeconomic factors. For these participants, the impact of PAU on their socioeconomic factors had negative implications for their QoL. Most

interviewees also spoke about the adverse impact of PAU on their job or career. For example, Tadhg talked about how alcohol resulted in him “losing jobs”. Mark also described how he got demoted in his job due to his alcohol use:

I'm getting a little bit bored of my job, doing the same thing in my job. I've been doing that job for 7 years, and I used to really enjoy it because I used to work out in the warehouse, the stockroom where there was lots of different things to do [sic] but, because of obviously drinking and cocaine and coming in late, missing days, they moved me on to the late shift on the floor, so all I'm doing now is packing shelves, it's just so repetitive, it's the same thing, so you're not really into it.

Most participants spoke about the negative consequences of PAU on housing. For example, Chloe talked about how things got so bad with alcohol, she was “evicted” from her home by her housemate because her “quality of life was terrible” and she wasn’t looking after herself. Robert spoke about how drink took “basically nearly everything” from him, including the opportunity to have his own house, which he felt he would have had except for the impact of PAU. Participants spoke about the negative impact of PAU on their finances. Hannah talked about how she had to borrow money from “everybody” because “nothing mattered, other than I had drink in my bag”. A few of the participants spoke about the negative impact PAU had on their education. Robert described how alcohol “took away a lot of opportunities” from him, including an opportunity he had to complete a college course as a fitness instructor. Several participants spoke about a lack of motivation around education due to PAU. For instance, Hannah talked about how, when she was drinking, she had “convinced” herself that she “wasn’t able” for college.

4.3.5.2 Benefits of recovery from PAU for socio-economic factors.

Participants spoke about the benefits of recovery from PAU for socioeconomic

factors. For these participants, these benefits seemed to have positive effects on their QoL. Several interviewees spoke about the positive impact of recovery from PAU on their finances. Daniel spoke about how he only realised when he was in recovery and on the dole, “the amount of money that [he] did spend” on alcohol. A few of the participants talked about the benefits of recovery from PAU for housing. For example, Conor spoke about how he got “housed by the council” in London due to completing an alcohol recovery program. Several participants talked about the benefit of recovery for their jobs or careers. Luke described how contentment for him in recovery was “going to work in the morning” and “looking forward to” it. One participant spoke about the benefits of recovery for their education. Hannah described how there had been a “massive improvement” in her life since entering recovery, and one of the reasons for this was that she was back in college.

4.3.5.3 Goals and desires for socio economic factors.

Participants

highlighted their goals and desires for their socio-economic factors. For instance, many participants spoke about their motivation to improve their lives by bettering their housing situation now that they were in recovery. Chloe talked about her living situation in recovery and how living in a hostel made her feel 'rubbish' and how she was “working really hard” to improve her living situation and “get out of there”. Mark also spoke about his desire for a new job and the benefits that could come from it.

Maybe as time goes on, [I'll] seek a new job, something better, something that I'm more interested cause I'm not interested in what I'm doing, which isn't good for the brain. Obviously, if doing something every day that you're interested in is obviously good for the brain, keeps you active, doesn't give you those thoughts about cocaine and drink, eliminates them.

Participants also talked about their goals and desires around finances. Robert spoke about how he was doing his best in recovery; however, he felt that maybe he could take “more control” of his finances. A few of the participants spoke about their goals and desires for education, jobs, or careers. For instance, Tadhg talked about a college course in IT support for companies as a new job in this area would help take his mind off things that were going on for him in recovery.

The fifth theme in phase one concerning participants’ meaning and experience of QoL was socio-economic factors. Participants highlighted the negative outcomes of PAU on socioeconomic factors, the benefits of recovery from PAU for socioeconomic factors, and their goals and desires for socioeconomic factors.

This chapter described the five themes drawn from the analysis of the interviews with individuals with PAU. These themes convey a complex, often paradoxical picture of alcohol use in relation to QoL. The next chapter will examine the findings from phase two and then both are discussed in Chapter Six.

Chapter 5: Findings from Phase Two

This chapter presents the findings of the second phase of the study, involving interviews with ten adults who self-identified as having, or had, a family member with problem alcohol use (PAU). The chapter presents the analysis of themes identified from the participants' interview data in thematic format. The aim of this phase of the study was to understand what quality of life (QoL) means to individuals with a family member(s) with problem alcohol use and to explore how they experience QoL in their daily lives. In some cases, additional material has been inserted in square brackets to clarify what participants meant based on the researcher's understanding of the surrounding context. While participants did not always refer directly to their family member's PAU concerning their meaning and experience of QoL, they knew the study topic, so it was assumed that they were referring to this unless stated otherwise.

Data analysis of this phase of the study involved categorising the findings into five main themes underpinning how QoL was understood and experienced by individuals impacted by familial problem alcohol use (FPAU). As described in the methodology chapter (Chapter Three), the data was analysed using Braun and Clarke's (2006) 6-step approach.

5.1 Profile of Participants

Ten adults, comprising four men and six women, who self-identified as having, or had, a family member or family members with PAU and who did not identify as having PAU themselves were recruited online and took part in interviews between August and September 2020. The average age of respondents was 49 years ($SD = 13.85$, range = 29–70). Due to COVID-19 restrictions all interviews took place on the online communications application Zoom. This was due to government guidelines and restrictions put in place due to the COVID-19 pandemic.

Three participants reported FPAU impacting them in adulthood, two reported it impacting them in childhood, and five reported it impacting them in both childhood and adulthood. Four participants reported that it was their father with the alcohol problem, one reported that it was their mother, and two reported it was both parents. Two participants reported that it was their son with the alcohol problem, and finally, one reported that it was both their wife and daughter. Table 4.1 contains a summary of the information on each participant in Phase Two. It also includes a summary of supports or treatments accessed by the family member/ participant.

Table 4. 1

Phase Two Participant Information

Pseudonyms	Sex (M/F)	Age	Family Member(s) with PAU	Life-cycle stage affected	Professional Support or Treatment for FPAU
Margaret	F	70	Father	As Child	One-to-One Therapy, Support Groups
Brian	M	65	Son	As Adult	One-to-One Therapy, Family Treatment Program
Roger	M	40	Father	As Child and Adult	One-to-One Therapy
Paul	M	59	Wife and Daughter	As Adult	One-to-One Therapy, Support Groups
Jennifer	F	36	Mother and Father	As Child and Adult	Family Treatment Program
Maeve	F	35	Mother	As a Child	None
Thomas	M	49	Father	As Child and Adult	Treatment in Psychiatric Hospital
Lizzy	F	51	Father	As Child and Adult	Family Treatment Program
Ann Marie	F	29	Mother and Father	As Child and Adult	None
Caroline	F	58	Son	As Adult	Family Treatment Program

5.2 Chapter Layout

See Table 4.2 for a summary of the themes and associated subthemes in phase two. In the analysis that follows, participants' quotes are provided to illustrate the themes; as described above, these participants have been allocated a pseudonym (of the same sex) to protect their identity. The following sections will report on each theme in detail. Section one gives the findings on participants' meaning and experience of QoL concerning their mental health and emotional wellbeing experiences related to FPAU. Section two gives the findings on participants meaning and experience of QoL concerning the importance of social connectedness and support. Section three gives findings on participants meaning and experience of QoL in relation to the difficulties of functioning in daily life due to FPAU. Section four is devoted to an in-depth review of the findings on the burden of role and responsibility and the association with participants' QoL. Finally, section five introduces the findings of self and identity issues arising in childhood due to FPAU.

Table 4. 2

Summary of Themes and Subthemes for Phase Two

Themes	Sub Themes
Mental Health and Emotional Wellbeing Experiences	Adverse effects of FPAU on mental health and emotional wellbeing
	How acceptance and hope around FPAU or gratitude and positive outlook despite FPAU can help mental health and emotional wellbeing
	Consequences of family members recovery or sobriety from PAU for mental health and emotional wellbeing
Importance of Social Connectedness and Support	Perceived lack of support from family, friends, or community
	Negative effects of FPAU on relationships and social connectedness
	Consequences of family members recovery or sobriety from PAU for relationships and social connectedness
	Positive aspects of relationships and social connectedness in relation to FPAU
Difficulties Functioning in Daily Life	Difficulties with General Day to Day Functioning
	Difficulties Living Normal Everyday Life due to Hostile Atmospheres or Tensions in the Home
	Difficulties Functioning Financially
	Difficulties Functioning as a Family Unit
	Difficulties with Physical Functioning including Sleep
	Dealing with Legal Troubles
Burden of Role and Responsibility	Burden of role and responsibility in adulthood due to FPAU in adulthood

Reflecting on the burden of role and responsibility in
childhood due to FPAU

The long-term negative effects of burden of role and
responsibility in childhood on adulthood

Self and Identity Issues
Arising in Childhood

False, Lost or Stolen Identity or Childhood

Not Understanding Self in Childhood

Hiding or Making Yourself Invisible in Childhood

5.3 Themes from Phase Two Findings

5.3.1 Theme 1: Mental Health and Emotional Wellbeing Experiences

“It was more the emotional pressure...all the time” (Ann Marie)

The first theme identified in the data that captured AFMs’ meaning and experience of QoL was mental health and emotional wellbeing experiences related to FPAU. Similarly to phase one, participants in phase two also gave a lot of weight and significance to the theme of mental health and emotional wellbeing concerning their meaning of QoL. They also had an understanding and wisdom concerning their experiences of QoL relating to their mental health and emotional wellbeing, which seemed to come from what they had encountered and undergone with FPAU in their lives. The subthemes identified within this theme were:

- Negative effects of FPAU on mental health and emotional wellbeing
- How acceptance and hope around FPAU or gratitude and positive outlook despite FPAU can help QoL

- Consequences of family members' recovery or sobriety from PAU for mental health and emotional wellbeing

5.3.1.1 Adverse effects of FPAU on mental health and emotional wellbeing. The

first subtheme within this QoL theme concerning the meaning and experience of QoL was the adverse effects of FPAU on mental health and emotional wellbeing. When speaking about the impact of FPAU on mental health and emotional wellbeing in adulthood, many participants spoke about the negative impact of current FPAU on their current mental health and emotional wellbeing. Some of the factors included were anxiety, depression, shame, trauma including abuse, fears, stress, difficulties with expression or emotions, and feeling insignificant. Participants spoke about issues around fear, anxiety, panic, worry, dread, or not feeling safe. For example, Caroline described how she was always "on edge and on tenterhooks" around her son and his alcohol use, and this would have a negative impact on her relationships with other family members, particularly her young daughter, who was only ten years old. Brian spoke about how he and the rest of the family "had no quality of life" as his son "was a constant worry" due to his drinking and it then "on edge" with a "fear of not knowing what was going to happen". Interviewees talked about depression, low mood, emotional pain, or sadness due to the FPAU in their lives. For example, Ann Marie described feeling "heartbroken" over not having the mother she knew she could potentially have if her mother did not drink. Paul described the mental impact and the "angst" he suffered due to FPAU. The impact of the actions of both my daughter and my wife...ex-wife...and worrying about my son in Australia as to whether or not he might follow the same trajectory - of course, affected me mentally. I seemed to always be in a state of angst, and the only thing that held me together was having a good partner and having built up a small coterie of trusted friends that I could talk to. That is the only thing that kept me from committing suicide. As I

said, I am still getting counselling. Some participants spoke about experiencing loss or grief in their life due to FPAU. Brian described one particularly intense moment of grief after his son who had PAU had passed away.

I had a particularly bad episode one night - I just broke down and started crying, and I couldn't stop. I'd say I cried for four hours non-stop...I don't know what it was - it was maybe a release valve or whatever

Participants described feelings of shame, embarrassment, or guilt due to FPAU in their lives. Paul described "the shame of it all" because he came "from quite a respectable background" who were "not drinkers" and who "would have been rather well-known in the community". Paul also described feeling foolish due to only having realised when he was in his mid-forties that he had been living with an alcoholic for the past twenty years. Interviewees also described feeling guilt in relation to PAU in their families. For example, Brian spoke about his son's suicide while he was drunk and how he would "go through it all happening" wondering "what could you have done?". Participants spoke about the abuse and trauma they experienced in their current lives due to FPAU. One participant, Paul, spoke about the "trauma" he experienced in "the initial stages" of living with FPAU. Lizzy also spoke about the psychological, emotional and verbal abuse she got from her father. She described how she "got more of the really bad moments with him" and how the abuse she got was "unreal". Interviewees spoke about being physically threatened or the potential of physical threat due to their family members PAU. Paul described how his daughter and wife could potentially be violent and that there had been "moderately violent" and "explosive" incidences between the two. Caroline described how her son could be aggressive and angry at times and how he threatened her.

He could come in, and sometimes he could be aggressive and angry...I went down to the kitchen and it was two o'clock [am] and I said to him 'you're up for work at

seven' and he took the bread knife and said 'get the fuck out of my face Ma, or you'll be sorry!'...I'd be afraid something might happen.

She also spoke about how she got threatened by someone over a debt that her son had.

Somebody that he owed money to...it was a bit of a threat...they were coming to do something to the house if we didn't pay him a couple of thousand euro...I remember actually handing that money over because I was afraid not to. I'd never dealt with that before

Participants spoke about regrets they had due to FPAU. For example, Caroline talked about how she felt that she had "wasted years worrying and thinking" about her son and his PAU when she shouldn't have how that was "time that I should have given to myself". Participants also spoke about their anger or resentments due to FPAU. For instance, Paul described how he still felt "bitter" and "sore" over his wife and daughter's PAU and felt he would probably take these feelings to his grave. Ann Marie spoke about how she would shout at people if she was arguing with them and partially blamed this on her relationship with her mother.

[I find that I am shouting] when I am arguing [...] with my partner or when I'm arguing with my parents. Especially lately, I think it's because [...] my relationship with my mam this year is just - worst - the worst it's ever been.

Respondents also spoke about suffering from stress or feeling pressure due to FPAU in their lives. For example, Ann Marie spoke about the "ridiculous expectations" she felt from her Dad who would "guilt" her into seeing him. Paul spoke about how he "was under so much stress at home" due to "worrying about [his] kids" and how this spilt over into his work life where he could be a bit "sharp" with work colleagues. Participants spoke about how FPAU led to their own emotional difficulties. For instance, Caroline described how she was emotionally tired and "wrecked by all that happened all those years" when dealing with her son's PAU. Participants also described negative thinking or having a negative outlook due to

FPAU. For example, Brian talked about how he “dreaded the weekend, where he’d [his son] get his [social welfare payment] or whatever he was getting” to spend on alcohol.

Most of the participants reflected on the negative experiences of FPAU for their mental health and emotional wellbeing when they were children. Participants spoke about how they suffered fear, anxiety, panic, dread or worry in childhood due to FPAU. Margaret described feelings she had as a child growing up with FPAU in the home, “I think the predominant feeling, if I was to go back and think, was anxiety”. A few participants spoke about how they felt insecure or unsafe in their home as children due to FPAU. Ann Marie described her life at home as a child and how “you couldn’t relax - you just didn’t know what was going to happen” because her mother “lashed out a lot”. Margaret described her insecurities from growing up in a home with FPAU.

The insecurity that there was no parent [deeply affected me]...A child needs someone to say, ‘look, you are safe’[...]We were shipped off to my granny...within three months, we were in an orphanage...there was no sense of security...My mother was ill, my father was a drunk, and that is it in a nutshell.

Participants also reflected on abuse and trauma as children. Some participants spoke about physical abuse due to FPAU. Lizzy remembered how her father was “rough and violent”, especially with her two older brothers. Roger spoke about the “different levels of abuse” in his childhood due to FPAU, and that “there was obviously physical abuse”. Maeve spoke about how she remembered her mother chasing her around the house “with her stick”. Ann Marie spoke about how her mother would take her anger out on her and “shout” and “throw” things at her. Participants also spoke about the emotional and mental abuse they experienced in childhood due to FPAU. Margaret spoke about how “a lot of children in that environment grow up very quickly” due to the “emotional difficulties and abuse” and how her and her

siblings “suffered at the hands of it”. Roger also spoke about the underlying “mental abuse” and the emotional impact of the emotional abuse from his father.

There was always the underlying emotional and mental abuse...that was always the worst part of it...you can never really fully understand during your formative years...the emotional impact by somebody who would say something to you a certain way or when they would act a certain way or flip.

Participants also spoke about verbal abuse they experienced in childhood. For instance, Ann Marie spoke about visiting her mother and how there “would be a screaming match – every time” and how she would “have to sit there and take it”. Respondents also spoke about other traumatic events they experienced in childhood due to FPAU. For instance, Maeve spoke about the time she found her mother after she had tried to take her own life by drinking “a mix of like, loads of alcohol and bleach and detergent, and she took all the tablets in the room”. Participants reflected on the emotional impact FPAU had on them as children. For example, Maeve talked about the emotional response of “feeling frozen” every time her mother drank. Thomas also talked about the “sadness, the anger, the upset” that his father brought into the house. Some participants described having difficulties as children expressing what was going on for them due to FPAU at home. For instance, Jennifer described how she was “in crisis, and nobody knew”, including herself. Lizzy also described how she was afraid to speak up as there was an expectation that she and her siblings should be “seen and not heard”. Several participants described feelings of shame or embarrassment in childhood due to FPAU. For example, Maeve spoke about an incident in a restaurant with her mother when she was a young girl, where her mother got very drunk, and she had to look after her, which she described as “humiliating”. Some participants spoke about the stress or pressure they felt as children due to FPAU. Ann Marie described her childhood home as “stressful” while Thomas spoke about the “different types of stress” that his father brought into the family.

Some participants talked about feeling alone or insignificant as children due to FPAU. For example, Roger described how he “felt like I was on me [sic] own pretty early” and “had to make choices for myself.” He also described how he “didn’t have the money, or the luxury of a parent that would help”. A few participants spoke about the anger or resentment they felt as children due to FPAU in their life. For example, Lizzy described how she “hated” her father and “hated” the life that she had to live as a child due to his PAU.

Many participants spoke about the long term effects of FPAU on their mental health and emotional wellbeing and indicated how their mental health continued to be impacted beyond childhood to the current day. Some participants who grew up with FPAU in childhood spoke about having fear, anxiety, panic, worry, dread, or not feeling safe when they became adults. Margaret spoke about how growing up with FPAU made her “riddled with anxiety and fears” as an adult and that she still had to “have to have a light on” which she said was “a direct result of the fears I had as a young person”. Maeve spoke about being very anxious and connected this to “how my mum and dad related and the things that I learnt when I was a kid” and that her experiences in childhood with FPAU “shattered my world view of ‘this is a safe place’”. Participants who grew up with FPAU also spoke about how these childhood experiences caused emotional difficulties in adulthood. Jennifer spoke about how she found dealing with emotions challenging as an adult after growing up with FPAU in childhood. She described her emotions as “bubbling up...just there under the surface” and used the analogy of a swan that “looks really calm, but the legs are going ninety”. Maeve spoke about how she had only begun to learn as an adult how “to recognise and to understand” her feelings due to childhood FPAU. She described how she was coming to realise how she would dissociate her emotions and therefore wouldn’t realise she was “anxious until after”. Participants who grew up with FPAU in childhood also spoke about

avoiding emotional pain related to their childhood or blocking out childhood memories.

Maeve spoke about how, as she grew into adulthood, she developed “an unhealthy relationship” with alcohol and that she drank to “drown out that pain” that she acquired in childhood. Thomas described how he did not “have a huge bank of memories of [his] childhood” and wondered if his “brain just blocked a lot of it out” because his childhood had been unpleasant. Thomas also spoke about how growing up with FPAU in childhood was associated with a mental breakdown that he had as an adult.

I actually had a mental breakdown three years ago...a lot of it was to do with financial problems...I over-compensated. I never wanted to be like my dad, so I never brought problems home with me...I ended up in a psychiatric hospital for a few weeks. I put that down solely to my childhood.

Participants spoke about how growing up with FPAU contributed to negative thinking or a more negative outlook on life as adults. Roger described how his outlook could be negative at times because “the anxiety is still there...not knowing what to come home to...expecting situations to be bad...thinking people feel bad about you, or that people have the same disdain as your dad had for you”. Participants who grew up with FPAU as children also spoke about their relationship with stress or pressure as adults. Roger related his tendency to overthink stressful scenarios which negatively impacted his mental health to his childhood growing up with FPAU. He described how he would “treat work like home, and if an issue happens, I get upset, or I over-think it and get very anxious and depressed”.

Some participants also spoke about having regrets as adults due to the impact of FPAU from their childhood. Margaret described how, when her children were young, she “should have been light-hearted and fun-loving instead of trying to “give them perfection that wasn't available” and that she “lost precious moments with them by what was going on in my head”. Some participants also spoke about depression, low mood, emotional pain, or sadness

in adulthood due to their experiences in childhood. Lizzy described a period of her life when she struggled with depression that she felt had built up within her over the years. She described how she had “just kept it all in so long” until it “all came out”.

A couple of participants spoke about how FPAU in their childhoods impacted their happiness in adulthood. For instance, Lizzy described how she felt “quality of life is to be happy” and that she didn’t think she had “ever been happy because there was always that black cloud there” because she never had a chance to fully embrace what happiness could be”. Participants also spoke about the mental and emotional strain of dealing with control issues and perfectionism as adults due to growing up in a home with FPAU.

Margaret: If you were to say to me, 'what did you bring negatively from all of your experience?', it's the insecurity and the want to make everything like Disney - a happy world, like the Walton's! No badness in it, you know? I hate anything like that!

Interviewees also spoke about how their experiences in childhood impacted their self-esteem or self-confidence in adulthood. For instance, Maeve described how she felt that her mother’s alcohol use when she was a child had impacted her confidence as an adult.

I am super...overly conscious always of what people think of me [...] it is not in a positive way, it's not like, 'everyone, look at me!' it's like 'oh god, everyone is looking at me!' and I've carried that - it's followed me through.

Maeve also spoke about her shame as an adult after growing up with FPAU in childhood and how she was “deeply uncomfortable in groups” and felt “exposed”. She described shame as “a really intense feeling that people are staring [...] and they are judging, and they all think we are terrible people [and that] our family is a mess”. Ann Marie spoke about the anger she felt towards her mother over her PAU because she felt that her mother “chose it”.

5.3.1.2 How acceptance and hope around FPAU or gratitude and positive

outlook despite FPAU can help QoL.

The second subtheme focused on positive emotions concerning mental health and emotional wellbeing. Participants highlighted how acceptance and hope around FPAU or gratitude and a positive outlook despite FPAU helped them to deal with FPAU and to improve their QoL. Many participants described their acceptance of their family member's PAU. For example, Brian explained how he never blamed his son for his drinking and seemed to find some peace in the idea that "some people are just purely addicted, and that's what happened to him". He explained how alcohol "hammered" his son straight away and how "once he took his first drink, that was it". A few interviewees who grew up with FPAU in childhood also spoke about acceptance in adulthood. Roger spoke about how he had gained acceptance around growing up with his father's PAU, that it was a "profound part" of his life, and "rightly and wrongly, it's a part of [his] identity". Interviewees described their hopes concerning FPAU. For instance, Paul described the hope he had for his children in that they could possibly "start to live a good and virtuous life and work hard." Brian also spoke about the hope he and his wife had that their son would eventually stop drinking. Some of the participants described feeling gratitude. For example, Maeve spoke about feeling grateful that she did not go down the same road as her mother and that she "reined" in her alcohol use after feeling like she may have had an unhealthy relationship with it in her twenties. Caroline spoke about her gratitude for her son overcoming his addictions.

[I am] grateful that at least he's got that addiction out of his life, and I'm not going to get a knock at the door or a call saying [...] 'your child has been found dead on the street because he drank too much'.

Jennifer described how despite what she went through as a child she still felt that most of the time she was "full of joy" and that she could still "see the good in people". Respondents who

grew up with FPAU spoke about the gratitude they now had in their life as adults. Margaret spoke about how she was grateful not to “have gone down the route [her] father had gone” as she did not have a “have a love for alcohol”.

5.3.1.3 Consequences of Family Members’ Recovery or Sobriety from PAU for Mental Health and Emotional Wellbeing and QoL.

The third subtheme within this QoL theme was the consequences of family members’ recovery or sobriety from PAU for mental health and emotional wellbeing and QoL. Participants spoke about the benefits of their family members’ recovery or sobriety on their mental health and emotional wellbeing and QoL. For instance, Caroline indicated, "I'm so grateful that for the last five years he's been okay without alcohol and drugs like - that's a big thing!". Paul also described his gratitude for his daughter’s recovery and felt “a little bit more confident “that [in recovery] she is not being destructive” whereas “before [in addiction] she was absolutely being destructive to herself”. Participants also reflected on the positives of their family member’s recovery or sobriety on their mental health and emotional wellbeing in childhood. For example, Maeve spoke about her childhood and how her mother’s periods of sobriety made her feel “happy or elated” and how she felt “delighted when she wasn’t drinking”.

Participants also spoke about the negative impact of their family members’ recovery or sobriety on their mental health and emotional wellbeing and QoL. Interviewees spoke about how their family members’ recovery or sobriety brought false hope, a false sense of security, or worry about relapse.

Ann Marie: I wish she didn’t have that year of sobriety because it showed me the mam I could have...[who] she chooses not to be...I wish she hadn’t had that because it gave me...sense of hope that I hadn’t had before, and I don’t want it.

Caroline described how she still worried about her son despite his sobriety.

I still worry, yeah [...] Who knows? Is there going to be a day where things are going to go very wrong again, and how do I deal with it this time? Because I certainly wouldn't be able to do what I did the last time!

Participants also spoke about false hope, a false sense of security, or worry about relapse when they reflected on their childhood.

Thomas: No matter how long he was off the drink, there was that constant fear when he'd come home, you know? 'Is he after drinking?' You become paranoid....I'd go right up into his face to see if I could smell drink off him.

5.3.1.4 Goals and desires for mental health and emotional wellbeing.

Participants spoke about their goals for their mental health and emotional wellbeing after their experiences of FPAU in childhood. For example, Roger talked about how he was going to “work on” his feelings of “anxiety” and “dread”. Maeve spoke about wanting “to get to a place” where the impact of FPAU in her childhood “no longer affects [her] quality of life” as an adult. Finally, participants spoke about taking responsibility for themselves as adults after growing up with FPAU as children.

Ann Marie: I know what work still needs to be done for myself just to find some peace with how my relationship is with my parents. Sometimes you have to make peace with the fact that the acceptance and the work will only come from me.

This theme identified in the data that captured the meaning and experience of QoL was mental health and emotional wellbeing experiences related to FPAU. The next theme identified in the data was the importance of social connectedness and support.

5.3.2 Theme 2: Importance of social connectedness and support

“I think to be present for another person is the most important thing” (Maeve)

The second QoL theme identified in the data relating to the participants' meaning and experience of QoL was the importance of social connectedness and support. Participants seemed to understand and recognise the importance of social connectedness concerning their meaning of QoL. They talked about the relationship struggles they endured due to a loved one's PAU and how this affected their experiences of QoL. They also sensed the importance of social support concerning their meaning of QoL. However, in their reality, they seemed to feel that they lacked support, especially around FPAU, which was also associated with their struggles concerning their experiences of QoL. In support of these findings, they also spoke about their relatives' PAU recovery or sobriety and how this affected their experiences of QoL and how they were able to improve their social QoL by trying to take positives from their life experiences. The subthemes identified within this theme were:

- The perceived lack of support from family, friends, or community
- Adverse effects of FPAU on relationships and social connectedness
- Consequences of family members' recovery or sobriety from PAU for relationships and social connectedness
- Positive aspects of relationships and social connectedness in relation to FPAU

5.3.2.1 Perceived lack of support from family, friends, or community. The first subtheme within the QoL theme of the importance of social connectedness and support was the perceived lack of support from family, friends, or community. Concerning the perceived lack of awareness of PAU in wider society and impact on support. Participants highlighted

the acceptance of PAU in society, Ireland's drinking culture, and a lack of professional support in the area of FPAU. They also spoke about how others misunderstood and minimized PAU and had a stereotypical view of what it was, and also how societies expectations around alcohol use impacted on them. Interviewees highlighted the negative influence of the normalisation of alcohol use and its widespread social acceptance. For example, Brian spoke about how he thought his son's problem drinking might have been "normal" and how he thought it might have been just a "one-off kind of thing". Participants also spoke negatively about the prominence of alcohol within Irish society. Jennifer spoke about the role alcohol played in her parent's meeting when they were younger and how alcohol was a significant factor in how people get together in general.

I wish they had never met at work in 1975, "drunk as lords", you know? Like, I know it's the way people met each other, and I know even now if you're not having a drink, you might not meet someone [when going out socially in Ireland], but drink aside, they weren't happy.

Respondents also spoke about the negative influence of Ireland's drinking culture. Caroline spoke about how "everything that Irish people do involves the pub" and that Irish people "seem to think drinking is great craic". Paul spoke about a conversation with a friend where he described how people in his parish judged others on their "ability to drink". Brian spoke about how people dismissed his concerns about his son's drinking and that heavy alcohol use seemed to be an acceptable part of Irish society.

We were very upfront about [son's name] and 'bout the drinking, and I actually said to numerous people 'this is going to end badly!' and they would say to me 'for god sake, stop, he's only growing up!' so it's like as if that's an acceptable part of growing up in Ireland. You go out, and you get smashed, you get hammered. Nobody thinks of the consequences of, you know, the parents sitting at home.

Lizzy spoke about the lack of support for families, especially in a country that was synonymous with alcohol.

Regardless of whether they've [family member with PAU] gotten treatment, [...] the family are still in turmoil...they've got no skills or tools how to deal with it; how to work with the new person...I hate to generalise about the Island, but we do have a lot of drink issues...there is no help there

Participants also highlighted the negative impact of others' (perceived) misunderstanding or lack of understanding around PAU. Brian spoke about his son's court case for drunken behaviour and how he thought the judge might have understood the situation and sent his son for alcohol treatment. Instead, the judge sent him to a juvenile prison for sixty days, and he felt this was unfair and came from a place of not understanding PAU. Paul also described a situation where he was going through a court case with his wife for a divorce and felt the judges in these cases unfairly sided with his wife.

The alcoholism led to the marriage break-up; which led to the court case, which led to fifteen years of financial...financial ruin for me...she used to drag me into court every two years...claiming for the most outrageous things...alcoholics and drug addicts can be very convincing...a judge [...] would find in her favour, and I'd be dumbed down again.

Thomas spoke about how there can be a stereotypical view of what alcoholism is, and this can lead to cases of children living with FPAU going unnoticed.

I think we have this image of children living with alcoholics as being children from maybe a very deprived or very poor background where it presents itself in school”
“there mightn't be lunches made...there could be physical abuse...we were quite poor, but it never presented itself that way

Participants highlighted others' lack of understanding of PAU and spoke about how others could minimise the impact of alcohol and PAU. Maeve spoke about how, as a child, she opened up and shared her problem around her mother's PAU with a friend, only for her friend to minimise the issue by comparing it to her own problems at home. She felt that this was also an issue within wider society and, therefore, found that the only safe place to speak about her problems was in counselling.

I remember bringing it up with a friend...she just kind of compared my situation...
'you are not the only one!', it was almost like, 'go away...your problems aren't
[legitimate]...we all have problems!'...I have found that the only safe place to really
talk about these things is therapy

Thomas spoke about how he did not like how people would flippantly talk and joke about alcohol, especially in front of his children.

I don't like people making a joke about 'oh I was so drunk last night I can't
remember!'...I was talking to a friend during the week...my daughter was standing
next to me...he asked me 'did you have any big sessions during the summer?'...I don't
like that kind of attitude towards alcohol in front of kids. I just don't think it's healthy.

Caroline spoke about difficulties expressing herself because of her feeling that she was overreacting about the situation with her son because people had the attitude of "sure, that's what we do: we go to the pub, we drink, we do all that sort of thing!". Caroline also described how she did not want others to see her as having an alcohol problem in her family and, therefore, she had difficulties talking to others about her son's issues with alcohol and drugs. She talked about how it would be easier to talk about her son if he was physically ill rather than having a problem with alcohol.

If somebody has a person in the family that's ill, you can talk to people about it and tell them that he's ill, but I didn't want people to know that...That this fella [her son] was drinking or taking drugs

Participants also spoke about a lack of support from family, friends, or the wider community around FPAU. Some of this perceived lack of support seemed to be related to the stigma of PAU or being unfairly treated due to having an alcohol problem. For instance, Brian spoke about his son and the trouble his PAU was causing and remarked that “you don’t get a lot of help in cases like that, you know - you are left to your own devices”. He highlighted that, when his son was in trouble with the law due to drinking, some police did not understand or empathise. When asked if the Gardaí had some understanding around the situation, his reply was: “there was one or two that didn’t, you know? I suppose, like everything, you know, you meet good people, and you meet bad people”. Paul spoke about his experience of being treated unfairly by the courts when going through a divorce from his wife who had previously taken much money from their joint account to spend on alcohol. It seemed he felt the judge did not take his wife’s alcohol problem into consideration.

I had to cancel the Visa card or at least get her off it...we went to court...the judge looked at me and said, ‘she said she spent the money - what do you want me to do about it?’ So that was the justice I got.

Ann Marie spoke about how she felt there was a lack of support for her from those around her in relation to her relationship with her father. She felt she needed someone to acknowledge this and tell her that the situation she was living in was “not right”. Caroline also spoke about a perceived barrier to getting help and support from others around her son’s PAU as she worried that she was over-reacting about the situation with her son.

You see, in Ireland, you have such a thing where some people think ‘sure, that’s what we do: we go to the pub, we drink, we do all that sort of thing!’ Am I sometimes over-reacting?

Many participants reflected on a lack of support from family, friends, or the wider community as they were growing up with FPAU in their homes. These participants described their experiences of not having parents, having a lack of guidance or support, or having negative role models in their lives as a result of FPAU. Participants described not feeling loved, cared about, minded, supported, or nurtured. Margaret described how she felt that children in homes with FPAU are “like flotsam and jetsam. They are just...the rubbish that comes after the drama, and they have to float along and make the best”. Jennifer described how her parents were there for her initially and her “needs were met” but then “very quickly things had to be shelved because they [her parents] were struggling and they were so unhappy, so quality of life for a number of years was greatly reduced”. Ann Marie described how she felt like “a bit of an orphan” even though she grew up with her parents due to their PAU. Roger described how a lack of support from his father when he was a child made him question himself and whether he was loved or should be loved. Thomas talked about his father passing away and the subsequent grief he had over the father that he did not have rather than the father he did have. Margaret talked about how her father with PAU put her and her sister into an orphanage because he could not look after them.

He used to cry and say, ‘you have no idea what it’s like putting your children in an orphanage!’ and I’d say, ‘for god’s sake, grow up! You don’t know what it was like to be a child put in an orphanage!’

A couple of participants described bad or irresponsible parenting due to FPAU. For example, Maeve spoke about how her mother drank alcohol when she was pregnant.

I'm the eldest child, and my brother was born when he was five, and he was 'autistic', but it looks like she did drink when she was pregnant. She drank when she was pregnant with me; she drank in the hospital after I was born; like, she was very dependent on alcohol.

Ann Marie described her father with PAU as "terrible" and how he was not around and that she did not have respect for him now.

My Dad wasn't around when I was a kid, so I don't have a lot of respect for him...he's always trying to guilt me into seeing him...the consequences of his addictions are kind of hitting him like a tonne of bricks now.

Lizzy talked about her father and how she "literally told him about how disappointing he always was and that you never could rely on him for anything" and that he was "never a dad" to her. Participants who grew up with FPAU as children also spoke about a lack of reassurance or support from other adults in their life. Roger described how he needed his mother or someone else to tell him "it was okay", that he was "doing good", and that the situation with his father and how he was behaving was "wrong".

5.3.2.2 Adverse effects of FPAU on relationships and social connectedness. The

second subtheme identified within the QoL theme of the importance of social connectedness and support was the negative effects of FPAU on relationships and social connectedness.

Participants spoke about the negative impact FPAU had on their relationships and social connection with their family member who had the problem with alcohol. Interviewees spoke about feeling disconnected, losing contact or falling out with their family member with the alcohol problem. Lizzy spoke about how she would ask herself if she liked her father and found it hard to say that she loved him. Ann Marie spoke about how she had not spoken to her mother in months and described her mother as "horrible" and "an absolute monster" who

“burnt a lot of bridges”. Paul spoke about his anger towards his estranged wife and how he would use opportunities when he was with his children to complain about her and her “drinking and her carry on [behaviours]” and that the “kids would be defensive, and the whole cycle repeated itself again”. Thomas spoke about how he threatened his father with PAU that he would not visit him with his granddaughter anymore and eventually stopped visiting him.

I said, ‘if you are going to live there [with his mother], I am not bringing [daughters name] up to see you’...he did move out. After a few years, he did start drinking again, and I stopped visiting him then.

Several participants spoke about difficulties communicating with, or being around, their family member who had the alcohol problem. Paul spoke about how his relationship with his daughter was “not a functional relationship” and that he was working on this in counselling. Ann Marie spoke about how herself and her mother with PAU were “not supposed to live together” and how her QoL would improve when she did not live with her. Caroline spoke about how her son with PAU did not care who he would “trample over” to get what he wanted. Some interviewees spoke about being let down by their family member with PAU. For example, Paul spoke about how his children with PAU had been a “great disappointment” to him as they didn’t share his values of working hard, minding your money, and getting a roof over [your head]”. Lizzy spoke about how growing up, she always felt “disappointed” by her father with PAU and that “when you are lied to for so long...you don’t trust people”. Paul spoke about feeling manipulated and having difficulties trusting his family members with PAU. For example, he spoke about how he felt he did not think he could “ever trust his daughter”, because of her “actions” and how “unreliable” she was.

Interviewees spoke about the negative impact of FPAU on relationships and social connection with others. Most participants spoke about how FPAU negatively impacted their

socialising or having relationships with others as adults. For instance, Brian spoke about how he understood how "relationships break down and fall asunder" due to another family member's FPAU. Paul spoke about how both his ex-wife and daughter tried to harm his relationship with his new partner.

When I met my partner, [name], I think that both my ex-wife and my daughter tried their best to work negatively against this relationship...that had its mental toll on me...We had made the commitment to each other very early on, that no matter what happens from either side - that we would stick together.

Ann Marie spoke about how she had difficulties having relationships with older women and how she "had massive conflicts with women who were in their fifties and sixties" and she related this to her relationship with her mother with PAU. Participants described a broken family unit potentially influenced by FPAU too. For example, Ann Marie spoke about how little her parents with PAU now interacted with her younger brother, who had special needs.

I don't know how much interaction my mam has with him [her brother] anymore; my Dad doesn't have any interaction with him [her brother] so it's just me and my aunty and he's [her brother] the most important thing [to us].

Respondents spoke about finding it difficult to truly express what was happening for them.

Caroline described her difficulties expressing what was happening for her around her son and his PAU.

I didn't really say much to my friends...I didn't say much to my family...it's a terrible thing to say, but it's easier to say [...] 'my child has cancer'...I always felt I could never say 'my child has a drug and alcohol addiction', you know? I needed someone to talk to.

Participants reflected on the impact of FPAU on their relationships and social connection with their family members with the alcohol problem during childhood. Interviewees spoke about feeling betrayed, let down, disappointed, or lacking trust in the person with PAU. Roger spoke about when he was a teenager and how he made the “conscious decision” “not to involve [himself] with him [his dad] anymore” because even when he would try and understand and “see it from his point of view”, his father always let him down due to his PAU and Roger would “always end up disappointed”. Ann Marie spoke about how every time they went to family events, her mother with PAU would “cause a massive argument” and she and her brother would have to be taken out of their beds and brought home early.

When I was a kid, [...] it was only when we went out to family events...she would always cause a massive argument...me and my brother being dragged out of the bed middle of the night because we'd have to go home

Interviewees described how their childhood needs around connection and relationships with their family members with PAU were not met. For instance, Margaret spoke about how she did not have a good relationship with her father with PAU as “he saw a parent in me, rather than a child”. Roger spoke about how his dysfunctional relationship with his father with PAU made him question if he was loved or if he should be loved. Thomas spoke about how, what he needed as a child was a father, but that his father “just wasn't there. [...] He was either drinking or just wasn't there”. A couple of participants spoke about having to stand up to their family member with PAU when they were children. For example, Lizzy spoke about her abusive father and how she eventually gained “a bit of respect” from him when she started to stand up to him and decided she “wouldn't put up with it”. A couple of participants spoke about how, as children, they had difficulties loving or respecting their family members with PAU due to their alcohol-related behaviours. For example, Ann Marie spoke about how she

didn't have a lot of respect for her father because he was not around and "he was a terrible Dad". Participants spoke about the impact of FPAU on their relationships and social connection with others in childhood. Some of the participants described broken family units in childhood due to FPAU. For instance, Thomas spoke about how his father "wasn't there" due to FPAU and that, eventually, his father left the family home. Several participants spoke about their difficulties connecting with others as children due to growing up with FPAU. For example, Maeve spoke about how FPAU resulted in her spending much time alone and being in a "very internal world" as a child. Lizzy also described how she always hated "being in gatherings". Jennifer spoke about how after realising how her life differed from her other relatives and friends she felt that she "couldn't have visitors over at the house" and she felt that "when you're a kid...that was big".

Participants spoke about the long term impact of growing up with FPAU on current relationships and social connections with their family members with the alcohol problem. For instance, participants spoke about growing up with FPAU in childhood and how it led to feeling disconnected, losing contact, or falling out with their family member with PAU. Roger spoke about his experiences growing up with his father and his PAU, how as an adult now he hadn't seen his father in six years, and how the relationship "was always quite strained". Other participants spoke about being let down by their family member with PAU and how this impacted on them as adults. For instance, Lizzy spoke about her experiences around her father's PAU when she was a child and how it led to a consistent feeling of "always feeling disappointed" as an adult. Participants also spoke about their experiences of growing up with FPAU and the negative impact it had on current relationships and social connections with others. Many participants spoke about how growing up with FPAU in childhood impacted their socialising or having relationships with others in adulthood. Several

participants spoke about how growing up with FPAU in childhood negatively impacted their relationships with other members of their own family when they were adults. For instance, Maeve described how her relationship with her father was “tempestuous” due to everything they had gone through with her mother and her PAU. Roger described how he did not get to see his mother as much as he wanted to as he was not visiting the family home anymore due to his father’s behaviour around alcohol when he was younger.

I don't see her as much as I possibly could because I don't go to the family home.

That's difficult...I meet her somewhere like [closest city]...it feels a bit covert, which it shouldn't be, but that's a decision I made.

Thomas described how he was sometimes a bit “short” [irate] with his mother and wondered if he subconsciously blamed her for his father’s PAU.

I don't blame my mother, but I wonder subconsciously is there something in my head that blames my mother...sometimes I feel I am being short with her, snapping with her, and that is not fair because it was completely not my mother's fault.

One participant, Maeve, spoke about the impact of FPAU in childhood on their parenting in terms of their relationship with their own children. She described how she affected her children by lashing out at them and that “it doesn’t take much to trigger me into shouting.”, which she attributed to “a trauma response” from her childhood due to FPAU. Participants spoke about how growing up with FPAU in childhood made it more difficult for them to connect with others or be around others in adulthood. For example, Ann Marie spoke about some of her difficulties in connecting with others.

I wish I didn't get so hurt so easily by other people's opinions because I still feel responsible for what they think of me, so any interaction I have with somebody it's like 'oh, this is all on me!' which is ridiculous!

Lizzy spoke about how growing up with FPAU in childhood potentially brought more loneliness or distancing from others during adulthood.

I never thought you know, I'd ever get depression, but I do [think] a lot of it is because I don't have someone in my life - it's more like maybe loneliness...you get to a certain age like you know you just want something in your life, and I suppose I've never had it.

Interviewees also talked about how growing up with FPAU in childhood negatively impacted their romantic relationships in adulthood. For example, participants described how FPAU in childhood brought conflict or dysfunction to their romantic relationships as adults. Maeve described how she could see that growing up with FPAU still affected her and how she was with her partner. She believed it played a significant role in why she had separated from her partner a few times. She described how they had “separated a few times” and how she “used to always blame him” but that she could now see that growing up with FPAU “plays a huge part”. Ann Marie spoke about how she found it hard to control her anger within a romantic relationship and related this to her relationship growing up with her mother with PAU.

It's kind of like the natural instincts...we made a system that, if I'm shouting at her [partner], she's like, 'you need to stop shouting at me', and whatever it is about it, I stop - I will stop...I do need that warning, that 'you're going too far now!'

Interviewees also spoke about difficulties starting and maintaining romantic relationships and a lack of trust or feeling unsafe in relationships due to their experiences growing up with FPAU in childhood. For example, Jennifer spoke about how she wished to be in a long-term relationship, but she struggled with it as she was not very trusting and felt her experiences with her parents influenced this part of her life.

I'm thirty-six, and I haven't had a long-term relationship!...your first example of a couple... it would be your folks... I'm trying to date, but I feel I'm falling at that hurdle a fair bit because of the chaos in the house.

Lizzy spoke about her struggles with romantic relationships, how she had difficulties trusting men, and how the “so-called role models” in her life when she was young “weren't really good”. She described how “that whole male Daddy figure wasn't there for me, and I don't trust guys, and I've never really had that many relationships”. Margaret spoke about how she “desperately clung to and sought security” and “someone [she] could trust” in relationships and described how she felt this need came from a “hyper-sense that I am ashamed of my background” and her instinctual perception that “people don't want me”. Maeve spoke about her “hypervigilance”, how she “can't trust” in relationships, and how she “reads into everything, and it causes so many problems in relationships”. Participants spoke about difficulties expressing themselves to others or presenting a false self to others due to childhood experiences with FPAU. For example, Margaret spoke about “presenting a cloak of respectability when you feel shame”. Jennifer described how she “just kept it all inside” due to her childhood experiences with FPAU.

5.3.2.3 Consequences of family member's recovery or sobriety from PAU for social connectedness. The third subtheme within the QoL theme of the importance of social connectedness and support was the consequences of a family member's recovery or sobriety from PAU for social connectedness. One participant spoke about how their family member's recovery or sobriety had a negative impact on their relationship with each other. Paul described the negative aspects of his relationship with his daughter while she was sober and in recovery.

When she [his daughter] was drinking, she could conceal it very well - she could be aggressive, but yet she could be very charming...Nowadays, particularly having gone through [treatment program], I find her a bit quieter, maybe more reflective - but still what we might call 'a bit sharp'... It's very hard to have a conversation with her because she draws everything back to this fundamental [new] religious belief...I am as unhappy with this relationship now as I was when she was drinking."

Several participants spoke about the benefits of their family member's recovery or sobriety on their relationship with each other. For instance, participants described improved relationships and communication. Lizzy described a period when her father was sober and how they "never had a father/daughter thing until I got to twenty-odd and we had maybe two years" and how "he was easier to live with" when he was sober. Caroline spoke about how they "get on really well all of us as a family" now that her son was in recovery and how "grateful [she was] for the fact that he's here". Several participants spoke about seeing the 'real' person or seeing a better person in their family member when they were in recovery or sobriety. Lizzy described a period of her father's sobriety and how he was "the person that he should have been and the person we should have known". Ann Marie and Maeve both described their respective mothers as "lovely" when they were sober and in recovery.

5.3.2.4 Positive aspects of social connectedness in relation to FPAU. The final subtheme within this QoL theme was the positive aspects of social connectedness in relation to FPAU. Participants highlighted some positive aspects of social connectedness despite FPAU. For instance, due to his recovery, Caroline said she could now talk to her son about his issues and that he had apologised for his behaviours.

I am grateful he overcame his addiction. We can talk about it a bit more now. He has said to me, 'I'm so sorry for what I put you through!' and I said, 'look it, you are okay now, that's all that matters! You got through it!'"

Brian spoke about how he felt the stress from his son's alcohol use would have been enough to break a relationship up but that he and his wife stayed strong throughout and stayed "singing from the same hymn sheet". Interviewees described positive relationships with others during childhood. Roger spoke about the "very close" relationship he had with his mother during his childhood and "if it wasn't for her", while he was dealing with his father's PAU, "life would be a lot different". He described his mother as "the person that's put things together when things went wrong". Jennifer, spoke about the importance of friends when she was a child growing up with FPAU and how friends were "everything". Thomas spoke about when he went to a support group for teenagers and "what [he] found good was just talking". He described "people discussing what happened them" and how it made him feel that "you are not the only one". Participants also spoke about helping others. Paul spoke about how he was able to connect with others as his experiences helped him to help others and that he was helping and supporting a family support group where he had previously got help himself. Interviewees also spoke about how their experience with PAU in childhood meant that they were able to help others when they were adults. Margaret spoke about how, through her experience with FPAU as a child, she "became a 'Rainbows' counsellor'" to help school children impacted by FPAU because "something in me wanted to help". A couple of participants spoke about how they wanted to help others. Maeve spoke about how she wanted "to do something that is helping people and supporting people".

The second QoL theme relating to participants' meaning and experience of QoL was the importance of social connectedness and support. The next QoL theme identified in the data was difficulties functioning due to familial PAU.

5.3.3 Theme 3: Difficulties functioning

“You have no life when you have something like that going on” (Brian)

The third theme identified in the data relating to the participants' meaning and experience of QoL was difficulties functioning due to FPAU. Functioning concerning the current study included anything FPAU related that impeded the individual from living a normal daily life or that took the individual's focus and attention away from being able to focus on a normal home or family life. These factors included disrupted daily routines, a chaotic home life, negative, tense or hostile atmospheres at home, or financial or legal trouble. It also includes how the family functioned as a whole and how much focus the individual with PAU took from the family from being able to function as a regular family unit. The subthemes identified within this theme were:

- Difficulties functioning as an individual due to FPAU
- Difficulties functioning as a family due to FPAU

5.3.3.1 Difficulties functioning as an individual due to FPAU. Participants spoke about the impact of FPAU on their general functioning as individuals. For instance, Caroline spoke about the impact of FPAU and how “it can take over your life” because “you think about it all the time, and it's always there in the back of your head”. Brian described how his son's PAU impacted how he functioned in relation to his sleep and job.

I often got up and left the house and went looking for [my son], wandering around the streets...after you put him into bed, you were afraid he'd throw up and he'd choke, you know? So myself and [my wife] would take turns sitting in the room with him...if it was during the week...[I would be] into bed at four o'clock [am] and up at six [am] for work - you were in some state for the day.

Brian also spoke about how his son's PAU took over and made it difficult to function, in particular around getting help or support.

It's very easy to say 'go and get help', but when you are in that frame of mind when all you are thinking about is next Saturday or next Wednesday or whatever, you know? You were only recovering from one bad weekend when you were thinking about the next one going to happen, you know?

Maeve reflected on her mother's periods of sobriety and the benefits to how she functioned as a child.

She was a very lovable and loving person when she wasn't drinking...she was really present for me at home. She'd get me up for school at half-six...having my breakfast on the table and those things matter because she showed me that she loved me...when she was in her drinking cycles - obviously I probably just got myself up.

Participants spoke about the chaotic nature of their lives and the atmosphere at home due to FPAU. Ann Marie described looking after her father and his PAU, especially after he lost his leg, as "chaos", "not normal", and "not right". Margaret spoke about how children who grow up in an environment with FPAU are nearly "attracted" to chaos because they are so "used to chaos" in the home. Jennifer described her childhood home as "utter chaos" due to her parents drinking. Thomas described how, as a child, he picked up on an atmosphere of secrecy around FPAU, which made things worse.

There was a lot of secrecy [...] she'd [his mother] make sure we didn't hear what was going on or what was being said [...] but as a child, you pick up on that of course, and sometimes that can make a situation worse because you don't know what is going on - it's all secretive - and that would have made that worse.

Participants also spoke about the impact of FPAU on their physical health. Margaret spoke about how she felt that children of alcoholics could be “stunted” in their physical development. Brian also highlighted how thinking and worrying about his son with PAU played “absolute havoc” on his physical health. A couple of participants described how legal issues due to FPAU had an impact on their daily life. For instance, Paul described how he had to deal with the legal issues that arose due to his daughter's drinking.

She rang me one Sunday night, and she was in tears, and she was in trouble, and she was in a police station...she had been drinking in the bar...she got up on a quad bike, was carousing through this island town...landed the quad bike right in the middle of this shop [window]!...she was being brought to court the next day, so I wired her some money to get an interpreter.

5.3.3.2 Difficulties functioning as a family due to FPAU.

Participants also highlighted how FPAU negatively impacted how they functioned as a family. They spoke about the chaos, tension, or uncomfortable atmosphere in their home. For instance, Caroline spoke about the atmosphere in her home due to FPAU and described her son's PAU as the “elephant in the room”. She also described how the atmosphere in their home was very tense due to her son's PAU.

The atmosphere in the house would be very tense, because then later on that night you'd never know what he'd come in like...tension between me and my

husband...we were all waiting for something to happen...I always thought if I can get ready for it to happen, I can make it good; I can change it.

Jennifer also reflected on the chaos and tension in the family home when she was a child and the memories of her parents having drunken arguments in the middle of the night.

It was chaos...you'd go to bed at a reasonable hour but you'd be lifted out of it [suddenly awoken] with arguments and the two of them shouting at each other...I'd try and intervene and be the peacemaker...I do remember waking up one morning and seeing [mother's name] there with a cast on her arm and not actually wanting to ask 'why' and I was quite young.

A few participants spoke about how they and their families functioned financially and how FPAU could bring on or contribute to financial difficulties or financial ruin. Some participants spoke about family members taking or stealing money, and potential difficulties for their family members to earn money for the family due to FPAU. Caroline described how things would "disappear from the house" and that she "couldn't leave anything worth anything" around the house because her son would steal things, including her money and credit cards, to help fuel his addiction to alcohol and drugs. Margaret and Thomas also described how their respective fathers drinking impacted how their families functioned financially. Margaret how her father "would come home from work half-eleven at night, money - all gone" and that the family "got to know not to expect that he would be there for us". Thomas how his family "would have been quite poor" and that he remembered "having a bowl of milk with potatoes in it for our dinner because there was no money in the house because he was drinking". Roger spoke about his father's PAU and the poverty that ensued at the end of each week due to his use of their income to buy alcohol.

There was times when we were hungry, particularly near the end of the week...when you had somebody like my Dad who would come in, take money, drink, smash up the house...it was just this force where you didn't know what to expect, at all.

A few of the participants spoke about how FPAU during their childhood influenced or controlled what the family did or how they lived. For instance, Lizzy described how family outings during her childhood always centred around alcohol.

There was always booze [...] the rare occasions that you would go out for a Sunday drive or something, like, you'd be lucky to get to the top of the road or get somewhere that you weren't stopping in a pub. It never went anywhere further than a pub, you know?

This theme identified in the data relating to the participants' meaning and experience of QoL was difficulties functioning due to FPAU. The next theme identified in the data was the burden of role and responsibility.

5.3.4 Theme 4: The Burden of Role and Responsibility

"I would have ran the house from a very young age" (Jennifer)

The fourth QoL theme identified concerning the participants' meaning and experience of QoL was the burden of their role concerning FPAU and the responsibility this brought on them. Participants seemed to take on the role of caretaker for their family members with PAU and, as a result, had to deal with extra responsibilities due to FPAU that would not usually be there without FPAU. These roles and the added responsibilities negatively impacted their QoL concerning QoL domains such as mental health and emotional wellbeing, i.e. anxiety

and worry, and daily functioning, i.e. if a regular daily routine was impacted by an issue arising due to FPAU. The burden of role and responsibility seemed particularly difficult for children impacted by FPAU. They took on the burden of responsibility for their family members' PAU and took on more advanced and mature roles in an attempt to care for their family members. The subthemes within this theme were:

- The burden of role and responsibility as an adult due to current FPAU
- Reflecting on the burden of role and responsibility in childhood due to FPAU
- The long term negative effects of burden of role and responsibility in childhood on adulthood

5.3.4.1 The burden of role and responsibility in adulthood due to current FPAU.

Participants spoke about added responsibility due to FPAU and described how they would have to take care of their family members due to the consequences of PAU. This burden of care brought with it factors that directly impacted QoL such as stress, strain, or worry. For instance, Paul spoke about how he had to look after his daughter and detox her at home when he found her after she had overdosed on “six bottles of vodka in two days and very nearly died”. Ann Marie spoke about the chores she had to do for her father and how she “thought that was fine” as “no one said anything”, but in retrospect felt it was “not a normal thing to do”. Brian spoke about the extra responsibilities he had trying to shield his younger daughter from the impact of his older son's PAU.

You didn't want - you know, anything to develop into a row or an argument. We were always conscious of that...we kind of shielded [their younger daughter] from him coming in at night, being drunk...she'd often see some of it anyway, and she did speak to me about it

5.3.4.1 Reflecting on the burden of role and responsibility in childhood due to

FPAU. The second subtheme identified within this theme was reflecting on the burden of role and responsibility in childhood due to FPAU. Interviewees described how they had too much responsibility or unhealthy responsibilities as a child due to FPAU. For example, participants spoke about how they took on the role of being a 'parent' or had extra responsibilities for other family members. Lizzy described how the "roles were kind of reversed" and that she and her siblings "became the adults and caretakers" when they should not have been. Ann Marie described how she felt she had a "massive amount of responsibility" and how she felt she needed someone to tell her that her parents' issues were not her responsibility. Some participants described how, as children, they monitored their family members' alcohol use or became highly sensitive or vigilant around it. For instance, Maeve described how and why she monitored her mother's behaviour and drinking behaviours.

I would come home from school, and I became this sort of 'monitor' - at home...I was monitoring everything and became attuned - if she even had a sip of vodka, like, I knew!...I was frightened of her when she was drunk, so it was a self-preserving thing: go and find the drink so she can't have anymore, and so she doesn't get scary!

A few of the interviewees described how they grew up quickly due to FPAU in the home and assumed a parental role. For example, Margaret spoke about how she grew up "very quickly" due to her father's PAU and the "emotional difficulties and abuse" that came with it. Some participants described how they would try and keep the peace at home when they were young. For example, Roger spoke about how his relationship with his father was "quite strained" because he always tried to "placate the situation and calm him down". Finally, a couple of participants spoke about blaming themselves or being blamed for things as a child that they felt they should not have been responsible for.

It wasn't my fault...There is nothing I could have done or didn't do that could have an impact on how they behaved...you can only but blame yourself at a certain stage...it must be something I have done...you just presume it's your fault

5.3.4.1 The long-term negative effects of burden of role and responsibility in

childhood on adulthood. The third subtheme identified within the theme of the burden of role and responsibility was the long-term negative effects of the burden of role and responsibility in childhood on adulthood. For example, Jennifer spoke about the continued weight of responsibility she felt as an adult due to her childhood experiences around her parents' PAU. She described how "a weight is still there. It's not as heavy, but it's still there" and that she still felt the need "to check in with them [her parents] and still kind of semi being the caretaker there". Participants also described the impact of FPAU in childhood on their role and responsibility as parents. They described the issues and difficulties around wanting their relationship with their children to be different from their relationship with their own parents and how they did not want their children to have the same childhood that they had. For instance, Margaret described how she was always trying to put order and quality into her children's lives that hadn't been there for her. Thomas spoke about how he never wanted to be like his father and never wanted his kids to have a father like him.

I suppose it wasn't until I started to deal with issues that I was able to pinpoint it and say, 'this is why I feel like that'. All I knew, when I was married and when I, when I had my two kids, is that I never, ever wanted to be like my Dad, and I never wanted them to have a father like I had.

Maeve also spoke about how she felt anxious as a mother due to her own experiences with her own mother.

My early childhood would have been really impacted...I have my own children, and it has really brought it up; it has really activated it for some reason... I suppose when you become a mother and if the mother was the issue in the home...it's put a lot of things into focus... I am very anxious...very very highly anxious as a mum, and I think it's all linked back to my early experiences with my own mum.

The fourth QoL theme was the burden of the role and responsibility. The final theme identified in the data concerning the meaning and experience of QoL was self and identity issues arising in childhood due to FPAU.

5.3.5 Theme 5: Self and Identity Issues Arising in Childhood

“When you are very small ... and you are trying to formulate your own identity and views of the world...you have this person who is supposed to be helping you...doing the absolute opposite...it does make you feel powerless and it does make you question yourself - the fundamental question of ‘Are you loved?’” (Roger)

The final theme identified within the data concerning the participants' meaning and experience of QoL was self and identity difficulties/ issues arising in childhood due to FPAU. Concerning this theme, participants associated their QoL with their identity, or lack thereof, as a child. Participants experienced feeling like they had their childhoods lost or stolen from them due to FPAU, or they felt that they created a false self or identity to help themselves deal with the problems in their life. Participants spoke about how they did not get the opportunity to learn about themselves or understand themselves as children, which was a

factor in their identity issues. They also spoke about metaphorically hiding or making themselves invisible. The subthemes within this theme were:

- False, lost, or stolen identity or childhood
- Hiding or making yourself invisible in childhood
- Not understanding self in childhood

5.3.5.1 False, lost, or stolen identity or childhood due to FPAU. The first subtheme was false, lost, or stolen identity or childhood due to FPAU. Participants spoke about growing up with FPAU in childhood and how they felt their childhood had been a false one where they couldn't be themselves, or that their childhood had been lost, stolen, or they were forgotten about. For example, Margaret spoke about how she felt her father had "stolen" her childhood due to his alcohol use. Maeve described how she "didn't have a great childhood" and that she will "never get that back". Lizzy spoke about how she did not get the chance to be herself as she felt she was "put in the background". Roger spoke about how he felt that he had "missed out on" learning about himself as a child and felt that the years he missed out on were the "formative years" where he would have learnt about his "morals" and "values".

5.3.5.2 Not understanding self in childhood due to FPAU. The second subtheme was not understanding self in childhood due to FPAU. A couple of participants spoke about their difficulties understanding themselves or not knowing who they were in childhood due to growing up with FPAU. Roger spoke about how, as a young boy, he needed a male role model to help him understand himself, but as the role model of his father with PAU was "so skewed, [...] wasn't there, or was abusive", he was confused and found it difficult to understand himself. Roger also talked about how he felt his father's issues with

alcohol compounded his identity issues and made him feel like an outsider in his home village.

I always felt that growing up, especially in Ireland, that if you had a family with lineage in the village, it was kind of like something that you could...you had a purpose and an identity. I felt growing up that that identity was difficult to...to gain in a rural village and kind of compounded by the fact of his issues.

Lizzy spoke about how she did not get a chance to know who she was due to being brushed aside due to her father's PAU when she was a child.

There is a constant battle because...it was always about them...there was always like, the tension... 'we've got to go somewhere and is he going to be on time', and 'is he going to make a show of [embarrass or shame] himself'...you don't get a chance to be yourself; you don't get a chance to know who you really are.

5.3.5.2 Hiding or making yourself invisible in childhood due to FPAU.

Finally, the third subtheme within this theme was hiding or making yourself invisible in childhood due to FPAU. A couple of participants spoke about how they hid themselves or made themselves invisible as children. Maeve spoke about how she learned to make herself "invisible" from her mother, and later in life, she used alcohol to help her with this. Lizzy also spoke about how she was "constantly hiding" as a child due to FPAU. She also spoke about feeling a sense of abandonment and feeling invisible and insignificant during her childhood as a result of FPAU.

There is a sense of abandonment and your identity and your childhood is kind of stolen...you kind of feel a little bit insignificant... 'Why aren't you here when we are all having dinner?'...because that was a rare thing.... 'Why aren't you here, helping with homework?'

The final theme identified within the data was self and identity issues arising in childhood due to FPAU. The following chapter will discuss findings from both phases one and two.

Chapter 6: Discussion

The current study investigated the meaning and experience of QoL for individuals with PAU and family members of individuals with PAU. Phase one of the study focused on the meaning and experience of QoL for individuals with PAU, and phase two of the study focused on the meaning and experience of QoL for family members of individuals with PAU. In phase one, the thematic analysis identified the themes:

- Mental health and emotional wellbeing
- Relationships and social connectedness
- Socio-economic and cultural factors
- Physical health
- Altered daily life functioning

In phase two, the themes identified were

- Mental health and emotional wellbeing experiences
- Importance of social connectedness and support
- Difficulties functioning in daily life
- The burden of role and responsibility
- Self and identity issues arising in childhood

The following section will first discuss the main findings of phase one concerning current literature and evaluate these findings within the broader understanding of QoL and PAU, with a subsequent discussion on the novel findings from phase one. This section will discuss key findings from phase one. Following this, key findings of phase two will be discussed and evaluated concerning the literature and broader understanding of QoL and PAU.

6.1 Discussion of Phase One Findings

6.1.1 Introduction

In phase one, the main themes identified concerning the meaning and experience of QoL for individuals with PAU were:

- mental health and emotional wellbeing
- relationships and social connectedness
- socio-economic and cultural factors
- physical health
- altered daily life functioning

Many aspects of the findings reflect what was discussed in the literature review. This includes that an individual's PAU, in general, can negatively impact their QoL in relation to psychological health (Killeen, Back & Brady, 2015; Karpyak et al., 2016), social health (Chou, Liang & Sareen, 2011; Lintzeris et al., 2016), physical health (Tsochatzis, Bosch & Burroughs, 2014; Dguzeh et al., 2018), and environmental health (Ghose et al., 2013; Upshur, Weinreb & Bharel; 2014). However, there were some additional insights and complexities within these themes related to PAU. These complexities highlight the potential for distinctions between an individual with PAU's QoL and those who do not have PAU. For example, there were some paradoxes within the themes. What is meant here by "paradoxes" is that, while participants spoke about how PAU negatively impacted their mental health and emotional wellbeing, relationships and social connectedness, physical health and daily functioning, they also highlighted how they drank alcohol for positive uses in these areas. These paradoxes show us the complex role that alcohol potentially plays within an individual's QoL. This contradictory role of alcohol was common throughout many themes and will be discussed under relevant headings below. Following this, some of the above

themes will be discussed to determine how information collected in the current study can deepen and broaden our understanding of QoL and, specifically as it relates to PAU, highlighting novel findings. The themes of physical health and socio economic factors are not discussed in the following paragraphs due to word count restraints and priority given to themes that were in common for both groups of individuals.

6.1.2 Mental Health and Emotional Wellbeing

The first theme identified in phase one was “mental health and emotional wellbeing”. This theme was divided into the subthemes:

- The adverse outcomes of alcohol use on mental health and emotional wellbeing
- Drinking alcohol to improve poor mental health and emotional wellbeing
- Consequences of recovery for mental health and emotional wellbeing
- Goals and desires for mental health and emotional wellbeing

All participants spoke about how their PAU negatively impacted their mental health, emotional wellbeing and, consequently, their QoL. These findings are consistent with the literature, which reports that problematic alcohol use can negatively impact an individual's psychological and mental health, emotional wellbeing, and, consequently, their general QoL (Okoro et al., 2004; Killeen, Back & Brady, 2015; Pasareanu et al., 2015; Karpyak et al., 2016; Patra et al., 2016). When speaking about the impact of drinking on their mental health and emotional wellbeing, participants from phase one mainly focused on negative moods, emotions, or thoughts, feelings of shame, guilt or embarrassment, regrets, issues around self-esteem and self-confidence, and feelings around anxiety and panic. These findings match those observed in earlier studies. For instance, long-term heavy alcohol use has been linked to neuropsychiatric conditions, for example, anxiety or depressive disorders (Ginieri-

Coccossis et al., 2007; Worden et al., 2015; Karpyak et al., 2016), dysthymia (Diaz et al., 2009), or daily stress (Ventegodt, Merrick & Andersen, 2003; Neupert et al., 2017).

Furthermore, factors such as stress (Rapaport et al., 2002; Antoni et al., 2006; Colovic et al., 2009), depression (Stein & Barrett-Connor, 2002; Brenes, 2007; Andriopoulos et al., 2013), and anxiety (Stein & Barrett-Connor, 2002; Wetherell et al., 2004; Brenes, 2007), have all been reported to be associated with lower levels of general QoL and featured in this study too.

Participants also expanded on their experiences of adverse emotional QoL due to PAU by speaking about intense mental or emotional comedowns from alcohol, hitting all-time lows or 'rock bottoms', and the potential for suicide or self-harm. These findings corroborate previous research in the area of PAU. When participants spoke about the comedowns or "hangovers" that they experienced due to alcohol use, they referred to the negative mental, emotional, and physical impact of alcohol withdrawal. Verster et al. (2020) define the alcohol hangover as "the combination of negative mental and physical symptoms which can be experienced after a single episode of alcohol consumption, starting when blood alcohol concentration (BAC) approaches zero". Previous research also reports on how alcohol use is associated with suicide, suicidal behaviour, and self-harm (Daly, 2006; Ginieri-Coccossis et al., 2007; Malone, 2013; Griffin et al., 2017; Mongan & Long, 2016). Furthermore, a national study in Ireland indicated that alcohol was the most frequently used drug reported in intentional overdoses (Daly et al., 2018). A study by Balazs et al. (2018) also found that lower QoL was related to a higher level of suicidal risk, which echoes this study's findings.

The findings from phase one concerning mental health and emotional wellbeing indicate that participants' alcohol use had adverse outcomes for their QoL. This point corresponds with the literature as PAU's negative impact on psychological health outlined in the literature review parallels the current thematic findings. However, the potential relationship between PAU and comedowns, suicide, or self-harm may be a finding that distinguishes this group of individuals concerning psychological and emotional QoL. Although the theme of psychological health and wellbeing may be ubiquitous within definitions of QoL (Chen & Storr, 2006; Luquiens et al., 2012; Frischknecht, Sabo, & Mann, 2013; Levola et al., 2014; Luquiens et al., 2015; Karimi & Brazier, 2016), the finding around comedowns, and alcohol-related suicide or self-harm, may indicate a distinction within the meaning and experience of QoL between individuals with PAU and those with no alcohol issues.

While participants spoke about how drinking alcohol negatively impacted their mental health and emotional wellbeing, all participants in phase one also spoke about how they drank alcohol to help them deal with or improve their mental health and emotional wellbeing. The literature tells us that there can be positive psychological benefits to light and moderate alcohol consumption (defined roughly as two or fewer drinks a day). These benefits include helping reduce stress, tension, depression, and self-consciousness and increasing overall affective expression, happiness, euphoria, conviviality, and pleasant and carefree feelings (Baum-Baicker, 1985). Peele and Brodsky (2000) highlighted how moderate alcohol use, defined as one drink daily for women and two for men (U.S. Department of Agriculture & U.S. Department of Health and Human Services, 1995), could have positive psychological benefits. However, they also noted that it was difficult to ascertain to what extent alcohol use brought about positive psychological outcomes and to what extent it was part of a complex

pattern of mutually reinforcing variables. Merrill and Thomas (2013) also reported that those who use less, or a smaller range of, adaptive coping skills, may have learned to rely on alcohol as a coping mechanism.

Many participants spoke about their PAU and its association with trauma from both childhood and adulthood. This included their experiences of traumatic events such as sexual abuse, witnessing domestic violence, or abandonment in childhood. They also spoke about experiencing traumatic loss of life or suicide as children. Participants also spoke about the trauma they experienced as adults and how they felt that it related to their PAU. For instance, they spoke about experiencing sudden, untimely, and traumatic loss of life within their families and circle of friends and experiencing traumatic events through their line of work (i.e., in the emergency services). Participants highlighted how they would drink to escape these recurring memories. These findings are consistent with the literature that shows an association between PAU and trauma (Butler & Bauld, 2005; Finger et al., 2010; Setlalentoa et al., 2010; Keyes, Hatzenbuehler, & Hasin, 2011; Breslau et al., 2013; Kishor, Pandit, & Raguram, 2013; Hope, 2014; Subbie-Saenz de Viteri et al., 2020). Overall, the trauma experienced by participants in phase one of the current study and their mental health and emotional wellbeing issues suggests a link between them. This relationship is consistent with the wider literature, which shows an association between mental health issues and traumatic events in childhood (Zarse et al., 2019) and adulthood (Connorton et al., 2012). Therefore, the mental health and emotional wellbeing issues experienced by participants in phase one may be associated with traumatic events that they experienced in their lives, and in addition, alcohol may be exasperating these issues. On the other hand, participants may have been drinking to help them deal with their trauma or other mental health and emotional wellbeing issues, which highlights a paradox within the findings.

Consistent with the literature on the association between mental health and emotional wellbeing and QoL, the findings in phase one suggest that participants drank alcohol with a desire/ intention to improve their QoL. However, the positive effects of the alcohol seemed only to be short term as participants' mental health and emotional wellbeing issues seemed to be compounded over the long term. The findings show that there could be a U-shaped relationship involving participants' alcohol use, where there are initial psychological wellbeing benefits to drinking, but that lead to eventual adverse effects.

The findings may also be related to the literature on drinking to cope. While many participants spoke about drinking with others and drinking for social reasons, all participants also spoke about regularly drinking alone. Drinking alone or solitary drinking is generally considered an atypical drinking style and potentially suggests a lack of control over alcohol use (Keough et al., 2015; Keough et al., 2016). The literature reveals associations between solitary drinking and alcohol use disorders, hazardous drinking, and elevated anxiety and depression (Skrzynski & Creswell, 2020). Solitary drinking is also associated with negative reinforcement factors, for example drinking to cope (Skrzynski & Creswell, 2020). While there may be many motives for drinking, research shows that people who drink to cope may be at heightened risk for alcohol problems (Kuntsche et al., 2005; Merrill et al., 2014; Stevenson et al., 2019). Furthermore, they are less likely to move away from excessive drinking patterns over time (Merrill & Read, 2010; Kenney, Anderson & Stein, 2018). Therefore, individuals who drink to cope may be a group of individuals at higher risk for solitary drinking, increased alcohol use, and experiencing alcohol-related problems (Wardell et al., 2020).

One theory, the Social Learning Theory of alcohol abuse, proposes that those who have a problem with alcohol may experience coping deficits and hold positive expectancies or beliefs that maladaptive behaviours like excessive alcohol use can be used as a generalized coping strategy (Britton, 2004). This theory appeared to hold true for some participants in the current study who believed that, if they consumed alcohol, they could cope better with life. If people use alcohol as a coping mechanism to improve their QoL, we should understand more precisely the role of alcohol as a coping tool to gain a deeper understanding of individuals with PAU's meaning and experience of QoL. With a more comprehensive understanding of alcohol as a coping tool, it may be easier to find suitable coping alternatives and concentrate on teaching individuals with PAU these practical coping skills to help improve QoL concerning mental health and emotional wellbeing. For instance, some treatment programs, such as the Keltoi residential program in Dublin, focus on emotional regulation to help with coping, sobriety and improving mental health and emotional wellbeing. Research has shown that emotional regulation strategies such as affect regulation training can effectively consolidate abstinence and, if used at the beginning of withdrawal, can promote the rapid implementation of new emotional regulation approaches (Nandrino et al., 2021). The findings of this study suggest a place and need for these treatment approaches in Ireland, and I return to this in the final chapter (page 254).

Many participants also spoke about the impact of recovery from PAU on their QoL. There are many ways to define recovery from PAU (Edwards et al., 2018). For example, the UK Drug Policy Commission (UKDPC) (2008) define *recovery* as "voluntarily sustained control over substance use which maximises health and wellbeing and participation in the rights, roles and responsibilities of society" (p. 6). On the other hand, the Betty Ford Institute Consensus Panel (2007) defines *recovery* as a "voluntarily maintained lifestyle characterised

by sobriety, personal health and citizenship" (p. 222). There is also an argument that abstinence is not required for recovery (Witkiewitz & Tucker, 2020). For the current study, *recovery* was defined as when an individual engaged with support for PAU (i.e. doctor, therapist) and made a conscious decision to abstain from alcohol.

All participants in phase one spoke about how recovery from PAU positively impacted their QoL in terms of their mental health and emotional wellbeing. Therefore, it seems that recovery from PAU would have positive outcomes for participants with PAU QoL. When talking about the benefits of recovery from PAU for their mental health and emotional wellbeing, participants in phase one spoke about feeling more content, grateful, accepting, enjoyment in life, and happier. They also spoke about having a more positive or laid-back attitude or outlook, improvements in self-belief and self-esteem, expressing themselves better or being more open, and improving self-care practices around their mental health and emotional wellbeing. These findings further support the idea that alcohol use had adverse outcomes for participants' mental health and emotional wellbeing and, subsequently, their QoL. The literature supports these findings. For instance, McGaffin et al. (2015) reported that abstinence from substances, including alcohol, was more commonly associated with flourishing mental health, and abstinent individuals (based on the 3-month follow-up period) experienced significantly better mental health during the follow-up periods compared to those who were not abstinent.

However, there were tensions within these findings that highlighted how alcohol might have been helping participants deal with their mental health and emotional wellbeing issues. Some participants from phase one spoke about how recovery from PAU negatively impacted their QoL in relation to mental health and emotional wellbeing. A few participants

seemed to struggle with this new way of life and seemed to miss the psychological and emotional crutch that alcohol gave them. Some literature supports this finding. For instance, Dennis, Foss, & Scott (2007) suggested the need for ongoing mental health treatment for individuals in recovery from problem substance use as they found in their study that mental health problems peaked during 1 to 3 years of abstinence.

Participants in the current study seemed to be aware of the potential benefits of recovery and abstinence from alcohol for their mental health and emotional wellbeing, and therefore their QoL. However, they still struggled to stay abstinent as participants regularly relapsed and struggled to maintain any extended periods of sobriety. We know from the findings that one of the reasons for participants drinking was to support their mental health and emotional wellbeing which may explain why they often relapse or have difficulties staying sober. When the crutch of alcohol is removed, these mental health and emotional wellbeing issues that participants are self-medicating to get relief from may become more obtrusive until they find it too challenging to remain sober. These findings add complexity to the simple narrative of alcohol being only and always negative and harmful and the need to find alternative coping mechanisms and supports.

For many participants in this study who spoke about PAU and its impact on their mental health and emotional wellbeing, a desire to improve their mental and emotional wellbeing to promote a better QoL was also a common theme. In phase one, all participants spoke about their goals or desires to improve their mental health and emotional wellbeing. Research has shown that focusing on life goals is associated with significant subjective wellbeing increases (King, 2001). Therefore, having mental health and emotional wellbeing

goals may have helped participants improve their QoL. Furthermore, one influential factor related to a higher motivation to engage in problematic substance use treatment is higher mental health problems (Hiller et al., 2009). This point also relates to the idea that motivation to engage in treatment can be attributed to patient activation, which refers to patients' knowledge, skills, and confidence in self-managing health conditions (Gao et al., 2019). This concept around motivation is where specific individuals are more active and effective in managing their (mental) health and healthcare (Greene & Hibbard, 2011). It may also be related to readiness for change or the *transtheoretical model* (Prochaska & DiClemente, 1983; DiClemente, 2005). The stages in this model are pre-contemplation, contemplation, preparation, action, and maintenance. The current study's findings reveal that participants may have been in the action stage. However, if we look at relapse, which can be included in the *transtheoretical model*, individuals may have come through all stages numerous times. These findings show the complexity of PAU in that individuals who want to improve their mental health and emotional wellbeing may struggle in doing so due to their issues with alcohol.

The finding around goals and desires for mental health and emotional wellbeing may be associated with the fact that all participants were undergoing treatment for PAU. The point that participants were open to improving their mental health and emotional wellbeing and seemed motivated to do so is a finding that those working in PAU treatment might acknowledge and build on to help them uncover specific individual pathways for an individual's recovery from PAU.

6.1.3 Relationships and Social Connectedness

The second theme within phase one was the relationships and social connectedness. The subthemes within this theme were:

- The negative impact of PAU on relationships and social connectedness
- Drinking alcohol to connect with others or to alleviate social disconnection
- Consequences of recovery for social connectedness
- Goals and desires for relationships and social connectedness

Participants in phase one spoke about how PAU negatively impacted their relationships and social connectedness and, subsequently, the social aspect of their QoL. They spoke about conflict and discord in relationships, difficulties dealing with others, isolation, being unmotivated to maintain relationships, being dishonest, manipulating others, feeling judged, worrying others, being unreliable, upsetting others, or being violent or aggressive. The literature supports these findings as research has shown that alcohol dependence is associated with a deterioration in social life (Ginieri-Coccossis et al., 2007), social isolation, and lower QoL (Chou, Liang & Sareen, 2011; Lintzeris et al., 2016). Furthermore, PAU can be related to more severe marital distress, a higher likelihood of divorce (Halford & Osgarby, 1993) and an increased risk of violence towards others (Jayaraj et al., 2012). For the most part, in the current study, participants from phase one openly spoke about how their PAU negatively impacted their relationships and social connectedness. This honesty highlighted how important and meaningful relationships and social connectedness were for participants' QoL. The findings around relationships and social connectedness indicate that participants' alcohol use had adverse outcomes for their social QoL. Although social domains are prevalent within definitions of QoL (Malet et al., 2006; Luquiens et al., 2012; Frischknecht, Sabo, & Mann, 2013; Levola et al. 2014; Post, 2014; Luquiens et al.,

2015; WHO 2019), the potential impact of PAU on relationships and social connectedness may be a finding that distinguishes this group of individuals concerning social QoL measures, particularly due to the ongoing conflict and discord in relationships or potential violence towards others.

Although participants spoke about the negative impact of PAU on their relationships and social connectedness, they also spoke about drinking alcohol to connect with others or to alleviate social disconnection, thereby contributing positively to their QoL. For instance, participants talked about drinking to socialise and connect with others. They also highlighted drinking due to difficulties connecting with others and drinking on feelings of isolation, loneliness, and negative feelings due to adverse interactions, e.g., conflict or feeling hurt. These findings around drinking to connect with others or alleviate social disconnection further revealed that participants' relationships and social connections were meaningful to them and played a positive role in QoL. The literature supports the findings around drinking to connect with others or alleviate feelings around social disconnection. For instance, Morito et al. (2015) reported that social isolation could lead to alcohol use disorder. This study highlights how that happens in practice, alongside the longer term negative effects, as participants spoke about drinking to connect with others but then that their relationships deteriorated due to their alcohol use.

The fact that participants spoke about poor social QoL due to PAU and spoke about drinking alcohol to improve relationships or connect to others may be associated with issues around social anxiety. Research shows significant comorbidity between social anxiety disorder and alcohol use disorders (Morris, Stewart, & Ham, 2005). However, while many studies have found a positive relationship between social anxiety disorders and alcohol use

disorders, others have shown a negative relationship or even no relationship (Morris, Stewart, & Ham, 2005). These factors could be down to certain traits within social anxiety disorder or potential moderating variables, for example, alcohol expectancies (Morris, Stewart, & Ham, 2005).

Research shows that factors such as loneliness and low levels of perceived social support are associated with lower levels of QoL (Verma & Kumar, 2018; Onal et al., 2022), while social support interventions are associated with improved levels of QoL (Cohen, 2013). Research also shows that reducing alcohol intake levels can improve QoL (Kraemer et al., 2002; Frischknecht, Sabo & Mann, 2013), while social support can help reduce levels of alcohol use (McDaniel et al., 2022; Tadros, 2022). Therefore, addressing social isolation in those with PAU may improve their level of alcohol use and their QoL in general.

Furthermore, as discussed earlier, solitary drinking is associated with drinking to cope (Skrzynski & Creswell, 2020). Again, this may reflect a cyclical or U-shaped characteristic in the current study around participants' drinking patterns concerning their relationships and social connectedness. For example, participants' PAU may cause relationship difficulties where participants might end up on their own and then drink more alcohol to cope with the negative feelings associated with this isolation, i.e., feelings of loneliness. The research supports this, as studies have shown that people can drink to cope with interpersonal problems (Carey, 1995; Carrigan, Samoluk, & Stewart, 1998; Lambe, Mackinnon, & Stewart, 2015; Patrick et al., 2018). Furthermore, drinking to cope with interpersonal problems has been found to predict drinking-related interpersonal problems (Dennhardt et al., 2016). This supports the notion of a cyclical or U-shaped characteristic of participants' drinking patterns concerning their relationships and social connectedness. This finding brings together complex

sets of research findings and emphasises the need to understand social aspects of PAU, to which this study contributes.

Finally, concerning the subtheme of drinking alcohol to connect with others or to alleviate social disconnection, some participants highlighted the social pressure to drink, the drinking culture, and the normalisation of drinking alcohol in Ireland. This reflects the difficulty of escaping drinking when socialising in Ireland and the research that reports that excessive alcohol consumption seems to be tolerated and somewhat accepted as a part of 'being Irish' (Tilki, 2006). Participants spoke about the influence of drinking culture in Ireland and the normalisation of alcohol use by those around them. They also spoke about government policies and societal and environmental issues and their influence on their alcohol use and alcohol use in Ireland in general. These findings are supported by the literature that reports that Ireland has always had a strong association with alcohol culturally, that it seems to be a significant component within the country's culture, identity, and socialisation (Stivers, 1976; O'Dwyer, 2001), and that levels of alcohol consumption may be explained through socioeconomic differences, cultural differences, or government policies on alcohol (Leon et al., 1997; Humensky, 2010; WHO, 2019). In trying to see how those with PAU understand and experience QoL, we can see the negative impact of Irish culture and societal norms around alcohol use on participants' alcohol use and, therefore, on their social aspects of QoL. We can see how culture may play a role in providing more opportunities for consuming alcohol in higher quantities and the resulting impact on an individual's QoL. These issues are essential to highlight, given the seemingly positive association of Irish culture with drinking, which for those for whom this becomes problematic, the consequences are severe, as evidenced in this study.

Participants in phase one also highlighted how their recovery or sobriety benefited their relationships and social connection, suggesting benefits for their QoL. These findings further support the idea that alcohol use had adverse outcomes for participants' relationships and social connection and, subsequently, their QoL. Participants described having better relationships, being more honest and open with others, and having positive connections and interactions. These findings are supported in the literature; for instance, Dennis, Foss, and Scott (2007) found that the duration of abstinence was associated with increased levels of social support and the number of clean and sober friends. While the findings of this study are not generalizable or quantified, they do also suggest these patterns. However, in this study another tension within the findings around recovery from PAU was that participants spoke about how recovery negatively affected their relationships and social connection, and therefore QoL. They spoke about losing connection with others and avoiding people or social situations. They also spoke about their fears of social situations without alcohol and losing connection with others due to not drinking. Again this reflects the strong association and identification that Ireland as a nation has with alcohol (Stivers, 1976; O'Dwyer, 2001; Tilki, 2006).

Participants' goals and desires for their relationships and social connectedness further emphasised the significance of relationships and social connectedness to participants' meaning and experience of QoL in phase one. These goals and desires included wanting a better connection with others, making amends with people they had fallen out with, wanting more support from others, wanting to help others, and wanting acceptance, approval, or validation. Research shows that social factors are positively associated with QoL levels (Hawton et al., 2011; Hnuploy et al., 2020; Choudhary et al., 2021). The desire for social connectedness is associated with people's basic needs. For instance, Maslow's Hierarchy of

Needs includes 'love and belonging' as one of its five fundamental categories of needs (Maslow, 1943; 1954; Hopper, 2020). The Self-Determination theory also proposes that 'relatedness' is one of three basic psychological needs required for ongoing psychological growth, internalisation, and well-being (Van den Broeck et al., 2016).

Participants in phase one had PAU-related social problems and, for the most part, had issues within most, if not all, of their meaningful relationships. Some treatment pathways, such as Alcoholic Anonymous, focus on connecting individuals with PAU with other individuals in recovery. This process occurs through group meetings where people share their stories or problems and gain a mentor or 'sponsor'. Research has shown the importance of connecting with other recovering individuals with PAU. For instance, a better relationship with a sponsor is associated with better recovery outcomes (Witbrodt et al., 2012; Young, 2012). Furthermore, alcohol treatment that includes the family or a partner, such as systemic family therapy, behavioural family therapy and behavioural couple therapy, are also reported in the literature to be well-established and efficacious treatment methods (Hogue et al., 2022). Therefore, these factors highlight the importance of focusing on relationships and social connectedness within treatment pathways to improve the individual with PAU's social QoL.

6.1.4 Daily functioning

Participants from phase one also spoke about daily functioning within their meaning and experience of QoL and highlighted the complexities of PAU within it. The subthemes within this theme were:

- The negative impact of PAU on daily life functioning and the benefits of recovery
- Goals and desires for daily life functioning

- Drinking to deal with daily life and general life problems

Participants described how they experienced low functional QoL due to their PAU. They primarily spoke about a lack of motivation around their daily tasks, self-care, and lifestyle in general. Lower energy levels may have been one of the reasons participants lacked such motivation as Conry et al. (2011) reported lower energy levels for those misusing alcohol. The findings around daily functioning indicate that participants' alcohol use had adverse outcomes for their functional QoL. Although domains related to functioning can be found within definitions of QoL (Malet et al., 2006; Frischknecht, Sabo, & Mann, 2013; Luquiens et al., 2015; Karimi & Brazier, 2016), the potential impact of PAU on daily functioning, particularly due to a lack of motivation or being under the influence of alcohol may be a finding that distinguishes this group of individuals concerning functional QoL measures.

The above findings were further supported when participants described how their self-motivation and functional QoL improved when they entered recovery from PAU. Noticeable improvements were mainly around taking more responsibility, improving self-care, having more discipline and commitment, falling into a routine, being more focused and having more determination. Participants also highlighted how these factors played a significant role in determining their drinking or recovery. However, while there were improvements for participants in these areas of their lives, when they were in recovery from PAU, none of them seemed to gain lengthy periods of sobriety and often relapsed. These findings may relate to the literature on motivation to change or readiness to change, especially concerning the *maintenance stage* in the *transtheoretical model* of motivation to change (Prochaska & DiClemente, 1983; DiClemente, 2005). To get to treatment, participants had advanced

through the first three stages of the *transtheoretical model*, namely, the *pre-contemplation*, *contemplation*, and *preparation* stages. They were currently in an outpatient treatment program and were in the *action* stage. However, it seemed that many struggled within the *maintenance* stage as nearly all participants had regular relapses despite the benefits they reported that recovery brought to their lives. These findings raise the issue of aftercare treatment and whether there is enough support for participants after leaving treatment.

Participants' lack of motivation due to PAU and its impact on functional QoL was an important issue for participants. They highlighted this further by speaking about their goals and desires for their daily functioning. These goals and desires included improving motivation, productivity, daily structure, discipline and focus, learning to live without alcohol, and participating in hobbies that did not include alcohol. In general, participants felt that these goals and desires were attainable if they dealt with their PAU and that achieving these goals and desires would lead to an improved QoL. Several participants also highlighted their goals and desires to get to a place where they could still drink in a controlled manner. Given the desire among these participants to continue to drink after treatment, this finding raises questions about how recovery is defined. As mentioned in the literature review, one definition of recovery may be abstinence; however, there are arguments that *recovery* can also be defined as controlled drinking (Higuchi et al., 2014; Costello et al., 2016).

Although participants spoke about how PAU negatively impacted their daily life functioning, they also spoke about how they would drink to function in their daily lives. For instance, one participant spoke about how she "drank to survive", while another participant described how she would "have to drink to make a phone call". Another participant described alcohol as a cushion to lie on to help him get through life, while another participant described

one day when she needed alcohol merely to get through the day. These examples show us how much participants relied on alcohol to help them function in their daily lives. The research supports these findings. For instance, Adams et al. (2016) evaluated a brief measure of alcohol use motivations, the Reasons for Heavy Drinking Questionnaire (RHDQ). The study reported high scores for drinking for stress relief, to "feel normal", or to avoid adverse physiological effects associated with alcohol dependence and withdrawal and to reinstate homeostasis. In a similar way to previous findings around mental health and emotional well-being and relationships and social connectedness presented above, these findings may suggest a cyclical or U shaped characteristic around participants drinking patterns concerning their daily life functioning. For example, participants may initially drink to help manage their day, but their drinking then results in their day becoming more unmanageable.

6.2 Discussion of Phase Two Findings

6.2.1 Introduction

In phase two, the main themes identified from the data of family members of individuals with PAU meaning and experience of QoL were:

- Mental Health and Emotional Wellbeing Experiences
- Importance of Social Connectedness and Support
- Difficulties Functioning in Daily Life
- The Burden of Role and Responsibility
- Self and Identity Issues Arising in Childhood

While the perspectives on QoL of family members of individuals with PAU are researched to a lesser extent than those with PAU, the themes found in this phase generally reflect what was discussed previously in the literature review. For example, participants

spoke about how FPAU negatively impacted their QoL in relation to mental health and emotional wellbeing, including experiencing trauma. However, some participants also highlighted the importance of QoL factors related to positive mental health, such as acceptance, gratitude or hope, to help them deal with their family member's PAU. Participants also highlighted the importance of social connectedness and support to their QoL. They spoke about how their family member's PAU negatively impacted their relationships and social connectedness, including feeling like there was a lack of support from those around them and the wider community. However, some participants also spoke about positive aspects of their relationships, despite having FPAU in their lives. This finding included how getting support from family and friends could help them deal with FPAU and also how they could help others due to experiencing FPAU. Most themes or subthemes have a section on current life, a reflection on childhood, and a section on the long-term impact of FPAU in childhood.

The theme "The burden of role and responsibility due to FPAU" as it relates to QoL is distinctly divided into these three sections. The theme "Difficulties functioning in daily life due to familial PAU" is divided into two subthemes with the first theme focusing on current life and childhood and the second theme focusing on the long-term impact of FPAU in childhood on functioning. Current functioning and childhood functioning were combined here due to the amount of overlap between the two subthemes.

Within the theme of "Mental health and emotional wellbeing experiences" as it relates to QoL, the subtheme of "Negative effects of FPAU on mental health and emotional wellbeing" is divided into the three sections mentioned above, while the subtheme of "Consequences of family members recovery or sobriety from PAU for mental health and

emotional wellbeing" is divided into two sections including current family members with PAU's recovery and a reflection on their family member with PAU's recovery from PAU during childhood. Within the theme of "Importance of social connectedness and support" to QoL, the subtheme of "Negative effects of FPAU on relationships and social connectedness" is divided into the three sections above, while the subtheme of "Perceived lack of support from family, friends, or community" is divided into two sections including the participants' current perception of support and a reflection of perceived support as a child. The final theme, "Self and identity issues arising in childhood due to FPAU" within QoL, is only a reflection on childhood. A discussion on the above themes follows, with an evaluation of them within our broader understanding of QoL.

6.2.2 Mental Health and Emotional Wellbeing Experiences

The QoL theme of Mental Health and Emotional Wellbeing Experiences is divided into the subthemes:

- Negative effects of FPAU on mental health and emotional wellbeing
- How acceptance and hope around FPAU or gratitude and positive outlook despite FPAU can help mental health and emotional wellbeing
- Consequences of family members' recovery or sobriety from PAU for mental health and emotional wellbeing

Participants in phase two spoke about the negative impact of FPAU on their mental health and emotional wellbeing and the trauma, including abuse, that they suffered. This subtheme divided into three sub-sections which were:

- The current negative effects of FPAU on mental health and emotional wellbeing,

- A reflection on the negative effects of FPAU on mental health and emotional wellbeing in childhood
- The long-term negative effects of FPAU in childhood on mental health and emotional wellbeing.

All family members highlighted how FPAU currently negatively impacted their QoL in terms of their mental health and emotional wellbeing. Topics discussed included depression, sadness, shame, anger, anxiety, worry, stress, and not feeling safe. These findings reflect the research where FPAU can negatively impact the wellbeing of the family (Butler & Bauld, 2005; Oreo & Ozgul, 2007; Yuen & Toumbourou, 2008; Hope, 2014; Alcohol Action Ireland, 2021a) and can increase stress, worry or exhaustion (Orford, 1994; Mize Menees & Segrin, 2000; Kirby et al., 2005; Anderson, 2011). Research also reveals that AFMs can experience higher levels of emotional insecurity (Orford et al., 2010; Tiwari, Srivastava & Kaushik, 2010), decreased psychological adjustment (Kirby et al., 2005), and feelings of loss and hurt that can lead to feelings of deep depression (Anderson, 2011).

When speaking about QoL-related trauma or abuse in adulthood due to FPAU, participants spoke about the traumatic experiences of living with a family member with PAU and the associated physical and emotional abuse. In the literature, FPAU is associated with experiencing trauma, abuse, and putting the safety and well-being of the family at risk (Butler & Bauld, 2005; Oreo & Ozgul, 2007; Yuen & Toumbourou, 2008; Hope, 2014; Alcohol Action Ireland, 2021a) through violence or aggression (Finger at al., 2010; Setlalentoa et al., 2010; Jayaraj et al., 2012), domestic violence, higher levels of partner physical abuse (Tiwari, Srivastava & Kaushik, 2010; Kishor, Pandit, & Raguram, 2013), increased risk of violence towards family members (Morrill et al., 2001), verbal and physical intimidation of family

members (Jackson & Mannix, 2003), and more severe injuries due to violence (Reider, 1988). Factors such as these can have severe implications for an individual's QoL (Brorsson, Ifer & Hays, 1993) and this was borne out in this study.

As reviewed in the literature, general QoL scales, HRQoL scales, and QoL scales related to PAU generally include mental health and emotional wellbeing domains (Chen & Storr, 2006; Luquiens et al. 2012; Frischknecht, Sabo, & Mann, 2013; Levola et al. 2014; Luquiens et al. 2015; Karimi & Brazier, 2016). However, AFMs' mental health and emotional wellbeing issues may be more persistent and profound for them than individuals who do not experience FPAU. For instance, the findings revealed that AFMs might live in a constant state of worry or stress due to their family member's PAU. They can also experience deep feelings of shame and trauma related to FPAU. While individuals who do not live with FPAU may also have psychological issues such as these, they may not be as extreme, deep-rooted or persistent as family members affected by PAU. Therefore, mental health and emotional wellbeing domains in general QoL scales, HRQoL, or QoL scales related to PAU might not be suitable when investigating the QoL of AFMs. The findings highlight the need for further investigation into AFMs' mental health and emotional wellbeing to determine more specifically what is needed to develop a scale for their psychological and emotional health QoL and this is further developed in the next chapter.

Family members also reflected on their childhoods and how FPAU impacted their mental health and emotional wellbeing when they were children. For example, they spoke about feelings of shame, embarrassment, anger, anxiety, worry, stress, and not feeling safe. These findings tie well with previous research findings wherein children can be significantly negatively affected psychologically and emotionally by PAU in the family and by parental

PAU (Grant, 2000; Dube et al., 2002; Gruber & Taylor, 2006; ISPC, 2010). Family members also spoke about having difficulties expressing their issues related to FPAU as children, as also illustrated by Adamson and Templeton (2012). They found that children of individuals with PAU can often find it difficult to ask for help. Further supporting evidence was reported by Klostermann et al. (2011), who reported that FPAU negatively impacted adult children of alcoholics coping strategies.

Previous literature has also highlighted the negative impact of FPAU on a child's confidence (Adamson & Templeton, 2012) and their reluctance to talk to people outside of their family unit about their issues due to the fear of the potential negative consequences or shame (Velleman & Templeton, 2007; Kroll & Taylor, 2009). These issues were echoed throughout this study, where family members spoke about often feeling alone, invisible or insignificant when they were children.

When participants spoke about their childhoods and QoL, they also spoke about traumatic events associated with FPAU. These events included a parent attempting suicide, experiencing physical abuse, witnessing aggression or violence between parents or towards siblings, being scared of parents due to their behaviour while drinking, and experiencing or witnessing emotional abuse, verbal abuse, and psychological or mental abuse in the home. These findings are consistent with research showing that children living with FPAU can more likely witness family violence (Finger et al., 2010; Setälä et al., 2010). This vulnerability to violence can potentially lead to psychological issues in adulthood, such as anxiety (Mize Menees & Segrin, 2000), low self-esteem (Rydellius, 1997; Mize Menees & Segrin, 2000) and living in fear (Kroll & Taylor, 2003). Furthermore, children living with FPAU are at risk of being victims of direct physical violence (Finger et al., 2010; Setälä et al., 2010). As

children are society's most vulnerable, the idea that a child's psychological and emotional health or even physical health could be under threat in their own home due to the use of a substance that is legal and extremely easy to acquire is quite alarming. These findings highlight the essential and immediate need for appropriate and adequate support for children whom FPAU impacts, further developed in the next chapter.

Family members also spoke about QoL as it relates to the long-term effects of living with FPAU in childhood and its impact on their mental health and emotional wellbeing as adults. For example, they spoke about anxiety, feelings of dread, not feeling safe, negative outlooks, stress, depression, emotional pain, shame, anger, and issues around self-esteem, self-confidence, and control (i.e., perfectionism). The continuation of negative impacts of FPAU from childhood through to adulthood is not surprising, and this link is a well-established one. For instance, Felitti et al. (1998) found that exposure to adverse childhood experiences, such as living with substance abuse at home, drew strong correlations to poor mental health in adulthood. Merrick et al. (2017) also reported a clear association between adversity in childhood, including household substance misuse, and poor mental health in adulthood.

The current study's findings highlight further how devastating and overwhelming an individual's PAU can be on their family members, who can struggle daily and throughout the lifespan with mental health and emotional wellbeing issues due to their family member's PAU and the associated trauma. The idea that the adverse effects of FPAU on mental health and emotional wellbeing can come at all stages in life highlights the issue that any family member in contact with FPAU will undoubtedly experience at least some adverse effects. Carrying the impact of FPAU in childhood through to adult life can lead to potential long-

term neurological, physiological, and psychological consequences in adulthood, including substance abuse, incarceration, and other co-occurring psychiatric problems (Dye, 2018). Therefore, it is critical to acknowledge how negatively impactful FPAU and the subsequent trauma or abuse can be for an individual's mental health and emotional wellbeing. Through understanding the meaning and experience of QoL of family members of individuals with PAU, we know that FPAU will almost certainly negatively impact their QoL. However, not all family members may look for or ask for help. Therefore, when an individual with PAU enters treatment, it may be beneficial to offer their family members the option to enter treatment to help them deal with their mental health and emotional wellbeing issues and concerns around FPAU.

The second subtheme within the theme of "Mental Health and Emotional Wellbeing Experiences" focused on positive mental health and emotional wellbeing as related to QoL. Participants described having feelings of acceptance or gratitude despite FPAU. At the same time, some spoke about having hope or a positive outlook concerning their lives concerning FPAU. Some participants also described how they were now taking responsibility for their lives and making up for troubled childhood due to FPAU.

There is not much literature on AFMs' general attitudes to life, perhaps related to an understandable focus on negative impacts in the research. However, positive emotions such as acceptance, gratitude or hope, or maintaining a positive outlook despite FPAU may be associated with the literature on maintaining personal boundaries around the family member with PAU. These boundaries would include not letting their family member's PAU-related negative behaviours impact them, and detaching from the person, even if they have passed on (Hazelden Betty Ford, 2021). This type of positively framed detachment is promoted in some

family support programs in Ireland and seems to be an integral factor in the recovery of AFMs (The Rise Foundation, Turas Counselling Centre, & North East Family Addiction Support Network, 2017).

Positive emotions or maintaining a positive outlook despite a family member's PAU may also be associated with resilience. Resilience contributes to positive outcomes, including surviving adversity, lower depression and longevity (Atkinson, Martin, & Rankin, 2009; MacLeod et al., 2016). Participants spoke about how they felt grateful whenever they got support around FPAU as children. The literature shows us how important it is for children to get support if they live with FPAU. Protective factors such as support from friends, family, or the community can improve the risk to children due to FPAU and help them achieve greater resilience (Velleman & Templeton, 2016). This theme of family, friends, or community support will be further discussed later in the chapter. The literature states that children impacted by FPAU and who grow up with chaos and instability at home can have lower self-esteem and even have genetic vulnerability than those not impacted by FPAU (Park & Schepp, 2015). However, these children can also have multiple protective factors, i.e., resilience (Park & Schepp, 2015). Therefore, the negative impact of FPAU on children may vary from person to person, depending on particular factors of resilience (Park & Schepp, 2015).

Some participants spoke about feeling brave as children despite living with FPAU, which might also be associated with childhood resilience. A systematic review of the research on children of alcoholics and their inherent resilience and vulnerability by Park and Schepp (2015) reported that their resilience is associated with age, self-esteem, self-regulation, academic and cognitive ability, and temperament. At a parental level, the child's

resilience is associated with attachment with a non-alcoholic caregiver, the quality of the parent-child relationship, how positive or consistent parents are, and parentification, which involves role reversal between the parent and child (Park & Schepp, 2015). At a familial level, resilience has been associated with the number of alcoholic parents, family density of alcoholism or the amount of alcoholism in the extended family, comorbid psychopathology in parents, family violence and conflict, family cohesion, adaptability and interaction, and other trustable family members (Park & Schepp, 2015). Finally, at a social level, the child's resilience can be associated with social support, extra-curricular activities, and later positive interpersonal relationships (Park & Schepp, 2015). As seen from this research, social connectedness seems to be an essential factor in a child's resilience, and this theme within QoL will be discussed later in the chapter.

The current pattern of findings revealed that FPAU and the associated trauma and abuse have negative implications for the mental health and emotional wellbeing of individuals throughout all stages of life, from childhood to adulthood. However, these adverse outcomes may be mediated by factors such as boundaries or resilience. Therefore, incorporating the relevant scales alongside QoL scales may be helpful in accurately evaluating treatment for AFMs. These factors would be worth further investigating concerning the meaning and experience of AFMs' QoL, further explored in the next chapter.

Participants in phase two also spoke about how the recovery or sobriety of their family member with PAU had positive implications for their QoL, specifically their mental health and emotional wellbeing. Therefore, their family member's recovery from PAU had positive implications for their QoL. Participants spoke about feeling gratitude that their family member had found recovery or sobriety, while other participants described their

childhood as being happier due to their family member's recovery or sobriety. Some literature supports these findings. For instance, Edwards et al. (2018) found that individuals with family members in recovery from problem substance use showed much greater psychological health and quality of life than their comparative cohort. Also, family members of individuals who had relapsed on a substance reported poorer psychological health and quality of life than those whose family members had not relapsed and were still in recovery.

This leads to some tensions found in the findings of phase two. While participants spoke about how the recovery or sobriety of their relative with PAU had positive implications for their mental health and emotional wellbeing, they also spoke about the adverse effects of recovery on these aspects of QoL. Participants highlighted how the issues around PAU do not just disappear when their family member stops drinking, that other addictions can take the place of the original one and that they can feel false hope, a false sense of security, and anxiety around potential relapse. There is a lack of research on the adverse mental health and emotional wellbeing that a family member experiences due to a relative's recovery from PAU. Therefore, there is a need for further research in this area. This finding also highlights the need for ongoing support for AFMs while the individual with PAU is going through their recovery. Both of these areas are expanded upon in the next chapter

6.2.3 Importance of Social Connectedness and Support

The second theme related to participants' meaning and experience of QoL was "Importance of social connectedness and support". This theme is divided into the following subthemes:

- Perceived lack of support from family, friends, or community
- Negative effects of FPAU on relationships and social connectedness

- Consequences of family members' recovery or sobriety from PAU for relationships and social connectedness
- Positive aspects of relationships and social connectedness in relation to FPAU

While some family members spoke about the importance of support from others, an important subtheme within this theme was the perceived lack of support from family, friends or the community. This QoL related subtheme is divided into three sections which are the perceived lack of awareness of PAU/FPAU in wider society and its impact on support, the current perception of support around FPAU, and a reflection on support around FPAU in childhood.

The subtheme of perceived lack of support from family, friends, and the community in the current study may be associated with participants' perception of a lack of awareness around FPAU in broader society. They felt that there were negative implications for the perceived social acceptance of alcohol use and felt that there was a misunderstanding of FPAU in broader society. They felt that society minimised the impact of FPAU and felt judged about having issues around it. These findings are supported in the literature, where research tells us that levels of alcohol consumption may be explained through cultural differences (Leon et al., 1997; Humensky, 2010; WHO, 2019). Furthermore, the findings also support the literature that states that Ireland has a strong association and identification with alcohol culturally and socially (Stivers, 1976; O'Dwyer, 2001; Tilki, 2006). Let us take, for example, Irish television advertisements. There are regular ads on Irish television that focus on awareness around mental health and smoking, but very rarely do ads that focus on awareness of the negative impact of alcohol on the individual or the family appear. The national charity for alcohol-related issues, Alcohol Action Ireland, suggests that there should

be more public awareness messaging on these issues, similar to campaigns that have been held in Australia and Finland (J. Hough, Alcohol Action Ireland, personal communication, 25 April 2022). Considering how much one person's alcohol use can negatively impact people's QoL, these points are worrying and point towards the need for education, laws or policy reform, treatment funding, and awareness, which will be discussed in detail in the next chapter.

Participants spoke about how they felt there was a lack of support or understanding for them when dealing with FPAU, and they felt like they had to deal with these issues alone. These findings are reflected in the literature where individuals affected by a family member's PAU can experience a lack of support (Orford et al., 2010; Orford, 2017). This perception of a lack of support or understanding and feeling alone with issues may be due to the points that AFMs can find it hard to ask for help, have difficulties locating or accessing support or treatment for themselves or their relatives, and feel shame around their issues related to FPAU, as discussed above (p. 225, 227). Research shows that there can be a general reluctance in AFMs to seek support (Church et al., 2018). They can have difficulties looking for support due to stigma, hopelessness and feeling undervalued by those who work in PAU treatment (McCann & Lubman, 2018). However, persevering, overcoming shame, and being open with trusted significant others, can increase help-seeking, while previous positive help-seeking experiences are also associated with improved help-seeking behaviours (McCann & Lubman, 2018).

These findings suggest a need for more focus on treatment and support for AFMs, emphasising reducing the stigma around PAU in society and letting family members know that there is support available and that they merit recovery as much as the individual with

PAU. Furthermore, to improve affected families' QoL, it would seem necessary to have support available to them when they are at the point where they feel they need it as the stress or strain AFMs' experience due to FPAU are mediated by the extent and quality of their social support, along with the positive or negative influence of their coping method(s) (Orford et al., 1998; Orford et al., 2010; Velleman & Templeton, 2003; Velleman et al., 2011; Toner & Velleman, 2014).

When participants spoke about their childhoods, they also felt a lack of support from family, friends, or the community. They spoke about issues such as feeling like they didn't have parents or experiencing a lack of guidance or support. They also spoke about a lack of reassurance or support from other adults in their lives, such as other adult family members or adults in the community. This finding suggests negative implications for QoL as research reports that levels of support and positive relationships with family members without a substance problem, or trusted adults outside of the family, can reduce risk to children, improve resilience, and make them feel cared for and less isolated (Newman & Blackburn, 2002; Bancroft, 2004; Forrester et al. 2008; Fraser, McIntyre & Manby, 2009; Osborne & Berger, 2009; Velleman & Templeton, 2016).

The above findings reflect the literature where early family experiences, particularly negative experiences, are associated with lower perceived family and friend support in young adulthood (Gayman et al., 2011). One study by Morey (1999) however found no significant difference in measures of perceived social support between children of alcoholics and children who were not affected by parental alcoholism. However, a more recent study by Nikmanesh and Honakzahi (2016) examined perceived social support in boys of drug-dependent fathers and found that perceived social support positively correlated with

resilience levels. The current study's findings around a lack of support from family, friends, or the community in childhood could again be related to the drinking culture in Ireland and how heavy alcohol use can be seen as the norm where individuals may not see the issues related to FPAU or choose not to acknowledge the issues due to their own heavy alcohol use. As heavy alcohol use is generally culturally accepted in Ireland (Stivers, 1976; O'Dwyer, 2001; Tilki, 2006), children and adolescents may receive mixed messages around FPAU. For instance, they may blame themselves, think they are the ones with the problem, or that they should be able to cope with the PAU in their family. These findings suggest that there should be more emphasis in the community on the issues related to FPAU. For instance, alongside school social programmes on mental health, child abuse, smoking, or drug and alcohol abuse, it may also be valuable to include separate educational programs and discussions in schools about FPAU. Therefore, children might know to access help and support if they are ever faced with problems related to FPAU. These points will be discussed further in the next chapter.

The QoL subtheme of "Negative effects of FPAU on relationships and social connectedness" was divided into three sections:

- The negative impact of current FPAU on relationships and social connectedness
- Reflecting on the negative effects of FPAU on relationships and social connectedness in childhood
- The long-term negative effects of FPAU in childhood on relationships and social connectedness in adulthood

Family members in phase two spoke about how FPAU in adulthood negatively impacted their QoL by impacting their relationships and social connectedness as adults. They

spoke about their relationship with their family member with PAU and how FPAU impacted it, such as losing contact, conflict, difficulties communicating, and trust issues. They also spoke about negative implications for their relationships with other family members, broken family units, difficulty socialising or having relationships with others, and difficulties expressing themselves to others. These findings reflect the literature where FPAU is associated with social isolation of the family (Setlalentoa et al., 2010) and a lack of friends (Tiwari, Srivastava & Kaushik, 2010). These issues could be down to the idea that family members affected by FPAU can experience social stigma (Orford et al., 2013) and distress in relationships (Kahler, McCrady & Epstein, 2003). Furthermore, FPAU is associated with lower marital satisfaction (Marshall, 2003; Floyd et al., 2006; Kishor, Pandit & Raguram, 2013) and higher rates of divorce (Rotunda, Scherer & Imm, 1995; Prescott & Kendler, 2001; Schneider, 2000; Collins, Ellickson & Klein, 2007; Setlalentoa et al., 2010). These were all factors brought up in interviews as participants highlighted the importance of social connectedness within their meaning of QoL.

At the same time, participants' social connectedness experiences were mostly troubled due to FPAU. As reviewed in the literature, general QoL scales, HRQoL scales, and QoL scales related to PAU generally include social domains (Malet et al., 2006; Luquiens et al., 2012; Frischknecht, Sabo, & Mann, 2013; Levola et al. 2014; Post, 2014; Luquiens et al., 2015; WHO, 2019). However, AFMs may experience different difficulties than individuals who do not experience FPAU in relation to social connectedness and support issues. For instance, with FPAU, there can be an increased risk for domestic violence, and there can be severe trust issues and hurt. Familial PAU can also increase difficulties with socialising and connecting with other people. Therefore, the QoL scales in circulation may not be truly

accurate for AFMs. Further research should be conducted with a specific focus on AFMs' social QoL.

When participants spoke about their childhood and the impact that FPAU had on their relationships with their family members with an alcohol problem, they spoke about feeling betrayed, let down, or disappointed. They also spoke about their needs not being met and a lack of trust, love and respect towards their family member. The literature reflects this as FPAU can expose children to negative role models (Setlalentoa et al., 2010) and harsher parenting styles (Finger et al., 2010). When participants spoke about how FPAU negatively impacted their childhood relationships and social connectedness with others aside from the family member with the alcohol problem, they also highlighted broken family units and difficulties connecting with others. The literature supports this as FPAU is associated with social isolation for children (Grant, 2000). At such an influential period of their lives in terms of social development and building connections and relationships with others, it is essential that children impacted by FPAU get the support they need to keep them engaged with others and develop healthy relationships. Furthermore, the fact that children can have difficulties in their closest relationships due to FPAU may yield issues within family treatment. For instance, if treatment goals are to "fix" the family unit or help it in some way, it may be difficult to implement positive change to improve the child's social QoL if the child's relationships are damaged or non-existent, or they do not have a positive role model in their life.

Family members in phase two also spoke about how FPAU in their childhood had more long-term impacts on their adult relationships, and thus on their QoL. For instance, they spoke about how FPAU in their childhood impacted their relationship as an adult with the

family member with PAU in ways such as relationship conflict, feeling let down, losing contact or feeling disconnected. There were also issues around relationships with other family members; for example, parents described taking their childhood issues out on their children. Haverfield and Theiss (2014) found that "low self-esteem and insecurity" and "anger and resentment" were issues that children of alcoholics faced in adulthood. These issues may also indirectly affect relationships. Furthermore, Klostermann et al. (2011) found that adult children of alcoholics focused on, and vented, their emotions as a coping strategy that could be indirectly linked to relationship problems. These findings highlight a need for AFMs to deal with their anger or self-esteem issues within an appropriate treatment setting if they are to improve their own social QoL; and highlights the need for access to such treatment options (discussed further in the next chapter).

The findings also revealed that FPAU in childhood seemed to affect relationships with others in adulthood. Family members highlighted difficulties socialising or connecting socially with others, difficulties expressing themselves or having issues around loneliness. These issues also included conflict or dysfunction in romantic relationships and a lack of trust or feeling unsafe around other people. There is some wider research to support these findings, and this research clarifies how this connects with QoL. For instance, one study by Vederhus, Timko, and Haugland (2021) reported that adults who had been affected by FPAU as children showed higher levels of loneliness than a control group consisting of individuals who did not grown up with PAU as children. Haverfield and Theiss (2014) reported on the issues children of alcoholics face in adulthood, and two of the themes that emerged from their analysis related to relationship difficulties were "romantic relationship problems" and "problems communicating". These findings may be related to the shame AFMs can feel around their family issues or the stigma around FPAU that they can struggle with. It highlights a need for

FPAU to be further highlighted within government policy where the stigma can be reduced, which could help reduce people's shame around it (see next chapter).

The above findings reveal that relationships and social connectedness were meaningful to family members of a relative with PAU. This point reflects the QoL literature and how social domains are standard within QoL frameworks (Hörnquist, 1982; Drummond, 1990; Bungay et al., 1996; McDowell & Newell, 1996; Schipper, Clinch, and Olweny, 1996; Testa & Simonson, 1996; Fallowfield, 2002; Malet et al., 2006; Luquiens et al., 2012; Frischknecht, Sabo, & Mann, 2013; Post, 2014; WHO, 2019). Therefore, concerning the meaning and experience of QoL and relationships and social connectedness, participants within the current study may not be much different from those who may not have issues with PAU within the family system. However, what appears to be different about individuals in the current study in comparison to those who don't have to deal with FPAU, is that they have the added burden of PAU, which can add further stress and strain to individuals' relationships and social connectedness. Individuals whom FPAU impacts may also have different expectations around what constitutes a healthy QoL due to the influence of PAU in their life. For instance, individuals whom FPAU impacts may have lower expectations for their family relationships due to the added stress and strain of PAU. Therefore, they may have lower expectations around what makes them happy or what constitutes a satisfactory QoL.

Participants in phase two also spoke about how their family member's recovery or sobriety positively impacted their relationships and social connection. They spoke about improved relationships and communication and how they could see the real and better person. Not much literature appears to be available on the impact of a family member's recovery from PAU on the social connectedness of the AFM. However, from the findings in

the current study, it appears that recovery from PAU can act as a positive factor for social connectedness. Nonetheless, there was also a paradox within this finding. For instance, some participants highlighted how there could still be difficulties in their relationship with their relatives with PAU despite recovery or sobriety. These findings are in accordance with findings reported by Higgins (1998), who wrote about the importance of treatment goals, such as improved family functioning rather than just the individual with PAU being abstinent. The author spoke about how early recovery can be a time of crisis for the whole family where adapting can be so difficult that the family may return to old behaviours to re-establish homeostasis. These findings reinforce the need and importance of aftercare programs and how family members should be included in their development and rollout (see next chapter).

While family members spoke about their QoL in relation to how FPAU negatively impacted their relationships and social connectedness, they also spoke about positive aspects of their relationships despite FPAU, such as the importance of connecting with others in their family/ social circle and building new relationships. They spoke about how their experiences with FPAU as adults and children had allowed them to help others who might have similar experiences. Being able to help others going through similar difficulties seemed to be meaningful for participants, and this was highlighted further by how they spoke about their goals and desires to help people impacted by FPAU in the future. This finding highlights how AFMs may feel comfortable connecting with those who have been through, or are going through, similar experiences and highlights the importance of facilitating individuals to connect with others with similar experiences and helping them if they can. Some participants spoke about how they had strong connections with other family members due to their collective experiences of going through FPAU. Others spoke about the importance of support

from other close relationships, such as friendships, to help get them through their difficulties due to FPAU in childhood. These findings reflect the literature where higher levels of social support are associated with lower levels of psychological distress (Kashubeck, 1994). Also, in other research areas, such as family members of people with dementia, peer support can reduce a family carer's perceived pressure, helplessness, and depression and improve their self-efficacy (Han, Guo, & Hong, 2020). The literature further highlights the importance of social support within an individual's QoL and facilitating people dealing with FPAU to connect with their families, broader social circles, and communities.

6.2.4 Difficulties Functioning in Daily Life due to Familial PAU

“You are always trying to fight fires” (Lizzy)

The QoL theme of “Difficulties Functioning in Daily Life due to Familial PAU” is divided into the following subthemes:

- Difficulties with Current Functioning and Functioning in Childhood due to FPAU
- Reflecting on the negative effects of FPAU on functioning in daily life in childhood
- The long-term negative effects of FPAU in childhood on functioning in daily life in adulthood

Participants in phase two spoke in general about how difficult daily life was and how it was difficult for them to function in daily life due to their family member's PAU, with clear impact on QoL. For instance, they described a chaotic home life and the daily issues they had to live with at home, such as conflict, tension, a hostile atmosphere, drama, and chaos. When participants spoke about their childhood and how FPAU impacted their daily functioning,

they similarly described a chaotic home life and related issues, such as conflict, tension, a hostile atmosphere, and drama. These findings are supported in the literature as FPAU is associated with violence/ aggression, higher levels of partner physical abuse, conflict, harsher parenting styles, higher rates of divorce, and decreases in marital satisfaction (Rotunda, Scherer & Imm, 1995; Finger et al., 2010; Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010; Kishor, Pandit, & Raguram, 2013). Issues such as conflict, tension, or a hostile atmosphere at home could affect an individual's daily functioning and QoL. These issues could mean individuals "walk on eggshells" around their family member(s) with PAU and behave in ways that attempt to de-escalate situations, please others in the family, or prioritise others family members needs (or others outside of the family) to the detriment of their own needs and functioning.

Furthermore, these issues might negatively affect a person's QoL concerning mental health, emotional well-being, or physical health. For instance, they could be living in fear or anxiety due to an imminent threat of violence or abuse, or there may be direct violence or aggression toward their physical health. These matters may also be associated with a lack of help-seeking behaviours where AFMs might find it more challenging to seek help due to the conflict, tension, or hostile atmosphere at home and the potential fear or anxiety associated with such an atmosphere.

Family members in phase two also highlighted difficulties functioning in their jobs due to FPAU, which is reflected in the literature where FPAU has been associated with unemployment (Mize Menees & Segrin, 2000) and job performance (Rotunda, Scherer & Imm, 1995). Consequently, AFMs could be missing out on potential opportunities within their careers due to FPAU. Also, if there is support available to them within their jobs to help

them improve the situation around the FPAU, they may not be able to ask for it as they may not know where to acquire such support.

Participants in phase two also spoke about financial difficulties and legal troubles in the family due to FPAU and how these impacted their daily functioning. These findings again reflect literature where FPAU is associated with financial difficulties and poverty (Grant, 2000; Orford et al., 2010; Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010), and legal trouble (Rotunda, Scherer & Imm, 1995). These issues highlight the need to make AFMs aware of emergency financial or legal support that might be able to help them improve their QoL. Steps to aid those suffering from financial difficulties due to FPAU are important as poverty is associated with poorer mental health in adults (Peterson, 2018) and children and adolescents (Nourbakhsh, Joshi, & Yorston, 2021). Furthermore, living in poverty has adverse effects on drug use (Lee & Clancy, 2020) and alcohol use (Jones et al., 2015; Jones & Sumnall, 2016), thus potentially contributing to an intergenerational cycle of problematic substance use and further problems for the family members' QoL. Dealing with issues such as these can contribute to the stress and strain an AFM can experience due to FPAU and highlights further the need for adequate family support to address such issues. As reviewed in the literature, general QoL scales, HRQoL scales, and QoL scales related to PAU sometimes include domains related to daily functioning (Malet et al., 2006; Frischknecht, Sabo, & Mann, 2013; Luquiens et al., 2015; Karimi & Brazier, 2016). However, AFMs have to function in an environment that is chaotic, hostile and filled with a tense atmosphere. They may also be more likely than those not living with FPAU to have difficulties with finances and in their jobs. Therefore, QoL scales need to allow for these factors that may impact AFMs more than others (see next chapter).

Participants in phase two highlighted how difficult it was to function daily as all their focus and attention would be on the family member with the alcohol problem. The family member with PAU would influence or control what the family did or how they lived. This issue seemed to leave individuals feeling that their needs had not been met, were not being met or did not matter. This issue was also true for participants when they spoke about their childhoods, where adverse conditions were described and constituted a very difficult developmental environment. In the existing literature, FPAU is similarly associated with neglect (Grant, 2000; Norman et al., 2012), can have negative consequences on family role functioning and how a family copes (Kishor, Pandit & Raguram, 2013) and can disrupt family life (Rotunda, Scherer & Imm, 1995).

For the most part, participants seemed to describe emotional neglect from their caregivers. Rees (2008 p.1) describes emotional neglect as the "dysfunction of the protective parental relationship on which children depend while they learn the skills needed for safe independence." They add that emotional neglect can affect essential developmental foundations, for example, perceptions of self, which is interesting as a finding in the current study was children's issues with their identity and sense of self. They argue that perceptions of self should be acquired through the mirror of attuned parenting, which can have lifelong consequences for stress regulation and for functioning effectively both independently and through relationships (Rees, 2008). Research also shows that neglect can lead to further problems in life, including poor impulse control, social withdrawal, problems with coping and regulating emotions, low self-esteem, poor intellectual functioning, and low academic achievement (Hildyard & Wolfe, 2002; Weir, 2014). PAU-related maltreatment of children, including child abuse and neglect, has also been associated with poorer QoL and psychosocial health (Hoefnagels et al., 2020). What is worrying about the findings

concerning emotional neglect is that others around the children, such as neighbours or teachers, did not seem to pick up on it. If they did pick up on it, they did not bring attention to it or attempt to do anything about it. Therefore, there may be a need for improved policies on screening children in schools or community settings around FPAU and the associated neglect and this is further picked up in the next chapter.

Familial PAU in childhood also seemed to have more long-term QoL consequences for daily life functioning. Participants spoke about how FPAU in childhood influenced how they lived their lives as adults and how the impact of FPAU hit them in adulthood. They spoke about carrying the weight of FPAU in childhood in their daily lives as adults and how they only learnt to live during adulthood. Hall and Webster (2007) documented that adults who had grown up with alcoholic parents reported a reduced sense of their ability to deal with the demands and challenges of life in comparison to a control group of individuals who reported no traumatic events in childhood. Ruben (2000) noted that, when children of alcoholics attempt to make sense of events or bring order to chaos, they usually fail, which can undermine their sense of influence in the world. This belief then follows them into adulthood and affects their ability to bring about changes in their lives (Ruben 2000) and the participants of this study vividly described this and related it to QoL.

As seen in this theme, familial PAU can have an overpowering influence on a family member's psychological functioning in day to day living, within their QoL experience. This issue could potentially bring up issues for treatment. For instance, if an AFM goes for therapeutic support to improve their QoL, the powerful influence of their family member with PAU may remain dominant throughout the therapeutic process and potentially hinder their progress. For instance, within the treatment process, AFMs may underemphasize their

own therapeutic needs by concentrating and giving attention to the relative with PAU. In other words, the individual with PAU may be a distraction from the essential or complex elements of the therapeutic process. This lack of engagement could impede AFMs from getting to the true nature of their issues. Therefore, it would be an essential issue to address early on in the treatment process.

6.2.5 The Burden of Role and Responsibility

Another QoL theme revealed was the burden of role and responsibility due to FPAU. This theme is divided into the subthemes:

- The current burden of role and responsibility due to FPAU
- Reflecting on the burden of role and responsibility in childhood due to FPAU
- The long-term negative effects of the burden of role and responsibility in childhood on adulthood

For family members in phase 2, their QoL seemed to be negatively impacted by the current burden of role or responsibility, sometimes known as "burden of care", due to FPAU. Participants spoke about having to take care of their family members with PAU due to the negative consequences of their PAU or having to take on more responsibility at home due to FPAU. These added responsibilities included dealing with overdoses or detox or getting a family member into rehab. These findings reflect in the literature as caring for a family member with a substance use problem can be a heavy burden for the family and those around them (Mattoo et al., 2013; Jiang et al., 2015; Orford et al., 2019).

Dealing with FPAU related issues, for instance, a family member's alcohol overdose would be a frightening and intense ordeal that could bring untold stress and strain to a family.

Furthermore, even after such an incident has passed, there can be ongoing worry or anxiety that a similar traumatic event might occur. Living with a constant concern or fear of what might happen concerning a family member with PAU was a matter that came up for participants within the theme of mental health and emotional wellbeing for family members' meaning and experience of QoL. The idea that they live with this daily anxiety distinguishes them from those FPAU does not impact and reinforces the need for adequate treatment and support for family members. Furthermore, suppose participants struggle with the burden of their role and responsibility due to FPAU, which leads to anxiety; there may be a negative compounding effect on QoL concerning multiple domains of QoL, such as functioning and mental health and emotional wellbeing.

The QoL- related theme of the burden of role and responsibility seemed to be particularly significant for the participants during childhood. Participants spoke about having too much responsibility or having unhealthy responsibilities as children. These findings included "growing up" quickly, taking on the role of parent, monitoring or becoming highly sensitive or vigilant around their family member's alcohol use, trying to keep the peace at home, or blaming themselves or being blamed for things that were not their responsibility. These findings are also supported in the problem drug and alcohol use literature. Bancroft (2004) found that children impacted by parental problem substance use can end up managing the family budget or pleading or shouting at parents to get them to stop or reduce their drug-taking. However, these methods often result in further conflict (Bancroft, 2004). Research also shows that children impacted by parental problem alcohol or other substance use can worry about what their parents are doing at home when they are in school. They can also try to stop their parents from using substances by refusing to leave the house (Advisory Council on the Misuse of Drugs, 2003; Bancroft, 2004).

The fact that so much of an AFMs psychological, emotional and physical energy can be taken up by an individual with PAU potentially means that they may struggle to reach their full potential. It may be helpful to review these findings through a theory that focuses on how individuals can reach their full potential, such as Maslow's Hierarchy of Needs (Maslow, 1943; 1954; McLeod, 2007). Looking at these findings through Maslow's theory, we see that AFMs may struggle with esteem needs or self-fulfilment needs due to focusing so much on the family member with PAU. These struggles may then limit their ability to achieve their full potential or self-actualisation. Furthermore, AFMs may be limited concerning their growth needs, such as self-actualisation, due to being stuck in deficiency needs, i.e. looking for safety, love, or belonging. It may be helpful to research these issues using Maslow's Hierarchy of Needs as a theoretical basis for investigating AFMs' needs, developed further in the next chapter.

Participants also spoke about how FPAU in childhood increased the burden of role and responsibility in adulthood and, therefore, its ongoing impact on their QoL. As mentioned already above, they spoke about feeling the weight of responsibility around the continued need to mind family members or act as their caretakers through their adult life. They also spoke about how such experiences impacted them as parents themselves, for instance, by not wanting their children to have the same childhood they did. The literature supports this finding. For instance, a study by Tedgård (2018) focused on how parents struggled with parenthood after an upbringing with substance-abusing parents. The study found that the effects of childhood trauma due to parental substance abuse were reinforced when individuals became parents themselves and had responsibility for a small child. These

effects included always being on alert, domineering feelings of anxiety, and being overprotective of their children.

The above findings link in with the intergenerational aspect of PAU, where PAU can be passed down from parent to child (Campbell & Oei, 2010). However, even if an adult child of an adult with FPAU does not acquire a problem with alcohol per se, they may have learnt negative behaviours and coping styles due to their parent's PAU. These negative behaviours and coping styles can pass down to children, where they might develop their own negative behaviours or coping styles, including PAU.

6.2.6 Self and Identity Issues Arising in Childhood due to FPAU

The next theme around QoL is of self and identity issues arising in childhood due to FPAU is divided into the following subthemes:

- False, Lost or Stolen Identity or Childhood
- Not Understanding Self and Hiding or Making Oneself Invisible in Childhood

Another finding related to participants' meaning and experiences of QoL was self and identity issues arising in childhood due to FPAU. For instance, participants described how they felt that their childhood had been a false one or that it had been lost or stolen. Literature searches indicate minimal peer-reviewed research articles on this topic; however, some non-academic literature refers to this theme. For instance, the documentary "Lost Childhood: Growing Up in an Alcoholic Family" by Emerald Yeh (2004) focused on interviews with children at a camp for children of alcoholics. In the interviews, children described "being mad [angry] because [they] knew [they] weren't going to have a childhood" and how they "just wanted to keep on being a kid". The documentary director, Emerald Yeh, described the

young children as speaking with a "wisdom and experience beyond their years", echoing the subtheme of a lost or stolen childhood. Some research has also shown an association between childhood issues around identity and trauma. For instance, a child's identity development may be hindered by a parent's trauma. Trauma can be shared across generations (Becker & Diaz 1998), and children can experience the suffering as if it were their own (Prager, 2003). Prager (2003) discussed how a child's fantasy world might replicate their parents' traumatic reality; their identity development can be severely impeded because they do not experience themselves as individuals living within their own distinct space in the world. The influence of this parental trauma can lead to lost generations and childhoods due to the loss of identities that are separate from their parents and their experiences (Prager, 2003). Research also reveals that experiencing childhood traumatic events can negatively affect identity development (Dereboy et al., 2018; Berman, Montgomery & Ratner, 2020). For instance, emotional neglect and emotional abuse can significantly predict identity confusion (Dereboy et al., 2018).

Participants also described how they did not understand themselves in childhood due to FPAU and "hid" or made themselves invisible. Some literature supports these findings. For instance, some research reports that children living in chaotic families are more likely to become withdrawn or build up a "fantasy world" (Turning Point, 2006), while other literature tells us that FPAU in childhood can result in social isolation (Moore, Noble-Carr & McArthur, 2010). Research has also found that, when no one in the family talks about the familial substance problems or when professionals only focus directly on the problems of the substance users, children impacted by FPAU can remain invisible as their needs are ignored (Kroll, 2004). The non-academic book "Gone to the Woods: Surviving a Lost Childhood" by well-known American author Gary Paulsen (2021) tells about the author's childhood and how

he survived parental problem substance use, neglect, abuse, witnessing domestic violence, and growing up fending for himself by escaping to the woods and surviving there in isolation by using survival skills he taught himself. The research and findings in the current study depict a stark image of how FPAU can impact a child's QoL, and highlight the need for support for children who are dealing with FPAU in their families, especially as there seems to be limited support for families impacted by PAU in Ireland (Western Region Drugs Task Force, 2015; Alcohol Action Ireland, 2021). Furthermore, since those in most need of support may also be those most reluctant to ask for help, the feelings of isolation and the burden of secrecy for children impacted by FPAU may be heightened.

The findings of phase two suggest a range of negative aspects concerning what QoL means to AFMs and the domains of mental health and emotional wellbeing, social connectedness and support, daily functioning, burden of role and responsibility, and self and identity issues. The findings also highlight how AFMs have experienced and experience QoL within these five domains and within a cultural context, the role of resilience and intergenerational PAU, and how difficult it may be to break this due to cultural norms. In conclusion, the findings suggest that there are various negative ways that FPAU can have on the QoL of adults and children in the family and highlight the negative impact of these experiences on an individual's QoL due to carrying the effects of FPAU from childhood through to their adult lives. The negative implications for QoL domains such as mental health and emotional wellbeing, social connectedness and support, and daily life functioning have been seen in previous studies, though with additional insights on the recovery of the individual with PAU and how it does not always lead to positive outcomes for the family member. This highlights the importance of recovery for the family member in their own right, which will be highlighted further in the next chapter. The role of trauma, the perceived

lack of support that families feel, the burden of role and responsibility, and self and identity issues in childhood have been made evident in this study. Furthermore, the adverse effects of FPAU may be compounded over multiple aspects of QoL.

The study highlighted that there can be positive factors within these domains where FPAU may contribute something positive to an AFMs QoL, such as the importance of getting support from others around FPAU and how experiences of FPAU can contribute to helping others. Furthermore, factors such as resilience may contribute to positive emotions such as acceptance or hope and could be a mediating factor concerning how FPAU impacts an AFMs QoL.

As there is a dearth of research on the meaning and experience of QoL of AFMs, these findings contribute to the knowledge base and help stakeholders and those affected understand if the QoL of AFMs is distinct from the QoL of individuals whom FPAU does not impact. These findings help the research, practice and policy communities look at current interventions and policies for family members impacted by FPAU and question if enough is being done. These interventions and policies will be examined further in the final section on the study's implications.

6.3 Synthesis of the Findings

For the individual with PAU, many of the findings in the current study support the literature on how alcohol can directly or indirectly impact an individual's QoL negatively in terms of their mental health and emotional wellbeing, relationships and social connections, daily function, physical health, and socio-economic factors. The findings furthermore support the literature concerning how recovery, in the more traditional sense of abstinence, can improve

an individual's QoL in these areas. However, the findings also extend our understanding of the meaning and experience of QoL for individuals with PAU. Recognising how these findings might help us understand the distinction between those with PAU and those without PAU concerning QoL is essential. For instance, it is necessary to realise the complexities and paradoxes associated with PAU or recovery (abstinence) concerning an individual's meaning and experience of QoL and the complex role of alcohol or its purpose in their life concerning their QoL. Researchers, practitioners, and policymakers should acknowledge how individuals with PAU may use alcohol to improve their QoL concerning their mental health, relationships and social connectedness, and daily functioning. Specifically, factors such as trauma, the potential for suicide or self-harm, and intense mental or emotional comedowns or all-time lows or "rock bottom" should be focused on concerning the individual with PAU's QoL. Factors such as the above are also critical concerning the measurement of QoL, where the available scales may not specifically include these important elements.

For the AFM, the findings in the current study also support the literature on how a family member's alcohol use can negatively impact an AFM's QoL in terms of their mental health and emotional wellbeing, relationships and social connections, and daily functioning. The findings also support the literature concerning how a family member's recovery (abstinence) from PAU can improve an AFM's QoL in these areas.

However, findings in phase two also extended our understanding of the meaning and experience of QoL for AFMs, which may help us understand distinctions concerning the QoL of family members affected by PAU and those who are not. For instance, there may be aspects of an AFM's mental health and emotional wellbeing that are distinct from non-affected individuals. For example, AFMs are affected by shame associated with their family

member's PAU. They may also be subjected to more trauma, abuse, or neglect than those not dealing with FPAU. There is also the feature that AFMs try to maintain a positive outlook or boundaries toward the family member with PAU to help them deal with FPAU.

In terms of relationships and social connectedness, it seems that support is vital to AFMs' to help them deal with FPAU; however, they also perceive that support is not there for them within their families, circle of friends or community. They also find it difficult to express what is happening for them. Affected family members have to deal with constant conflict and tension within their relationships, and they can develop trust issues due to FPAU. There can be ongoing chaos and tension in their homes, and they can take on the burden of a more responsible role within the family, especially during childhood. Also, during childhood, they must deal with factors such as confidence and identity issues. Furthermore, even if the family member with PAU enters recovery (abstinence), AFMs may still have deep feelings of worry and anxiety, especially about relapse. These are factors that researchers, practitioners, and policymakers should take on board.

It should also be acknowledged that AFMs' experiences can differ depending on the relationship with the person with PAU. For instance, children impacted by FPAU can carry lifelong problems within their mental health or social domains of QoL, possibly due to the PAU-related trauma, abuse, or neglect they experienced as children. In contrast, an adult who only experiences FPAU later in life may not experience the same long-term effects, i.e. once their family member enters recovery or becomes abstinent, they return to living a more regular and fulfilled life quicker. There are no QoL scales specific to AFMS, so the above factors should be acknowledged if or when a scale is developed.

Chapter 7: Conclusion

PAU affects individuals who are experiencing it themselves and their families. Therefore, the impact of PAU on an individual's QoL and that of their family members are critical areas for further study. This study gathered new and original insights into that for both sets of people. The following chapter includes a summary of the new knowledge and significance of the findings, the study's strengths and implications, the limitations of the study and, finally, reflections on the study and the researcher's role and position in it.

7.1 New Knowledge and Significance of Findings

The current study's findings expand the existing research base and have important implications for policy, practice, and theory. These findings include the negative impact of PAU on the individual and the family members' QoL, the benefits or not of recovery, the negative impact of FPAU on childhood, the lack of support for family members impacted by PAU, the potential positive role that alcohol can play in a person's QoL and finally, the role of trauma. Although there is a growing body of literature to support the link between QoL and PAU (Malet et al. 2006; Laudet, 2011; Luquiens et al., 2012), the current study's findings help us to understand the nature and extent of the association between PAU and specific domains of an individual's QoL; in particular, for AFMs. There are some scales that focus on the measurement of QoL for individuals with PAU (Drummond, 1990; Malet et al., 2006; Luquiens et al., 2015), and, while there is an increasing body of literature that focuses on how PAU impacts the family (Orford et al., 2010; Joolae et al., 2014), there is still little research on specific QoL measures for AFMs.

Similarly, trauma has been an area that has been researched a lot in the area of PAU, and many studies have highlighted its association with PAU (Volpicelli et al., 1999; Bombardier, 2000; Butler & Bauld, 2005; Kessler et al., 2005; Oreo & Ozgul, 2007; Yuen & Toumbourou, 2008; Breslau, 2009; Finger et al., 2010; Khoury et al., 2010; Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010; Keyes, Hatzenbuehler, & Hasin, 2011; Breslau et al., 2013; Bohnert, & Luo, 2013; Kishor, Pandit, & Raguram, 2013; Hope, 2014; AAI, 2016; Subbie-Saenz de Viteri et al., 2020). The current study further highlights how trauma is associated with PAU and how an individual's PAU can have a traumatic impact on those around them. As we know, trauma can lead to addiction or other psychological issues, which may contribute to a cycle of addiction and trauma that is difficult to break out of for both individuals with PAU and AFMs.

Another key study finding was focused on the impact that FPAU had on children. Although none of the interview questions mentioned childhood and, while it was never intended for participants to speak about their childhood, it seemed necessary for many to speak about it in order to demonstrate the meaning of QoL to them. Children were impacted by FPAU similarly to adults; however, there were additional issues due to FPAU in childhood that impacted the meaning of QoL for them. For instance, there were issues around identity and self and the burden of role and responsibility they bore. These findings are important for future research and for practice. Although some literature reports on the burden of responsibility or burden of care for family members affected by FPAU (Bancroft, 2004; Jiang et al., 2015), there is limited research available on such issues, in particular, for children affected by FPAU and their issues around identity and self.

Another important finding was the perceived lack of support felt by AFMs. This finding included the perceived lack of support from family, friends and the community for family members, while it also referred to a lack of awareness about PAU in wider society and the culture of drinking in Ireland. This finding is important as we know individuals affected by FPAU can experience uncertainty, worry, and a lack of support around these (Orford et al., 2010; Orford, 2017), and the current study supports these previous findings. It seems more needs to be done to support such individuals, especially in a country with high levels of binge drinking (WHO, 2014; Alcohol Action Ireland, 2019), where excessive consumption seems to be tolerated and somewhat accepted (Tilki, 2006), and where alcohol seems to be a significant component within the country's culture, identity, and socialisation (Stivers, 1976; O'Dwyer, 2001). Furthermore, the literature shows us how important it is for children whom FPAU impacts to get support (Newman & Blackburn, 2002; Bancroft, 2004; Forrester et al., 2008; Fraser, McIntyre & Manby, 2009; Osbourne and Berger, 2009; Velleman & Templeton, 2016).

An additional apparently novel finding from the study centred around the role alcohol played in people's lives. It seemed that alcohol could potentially play a positive role in people's QoL. This finding was especially valid concerning participants' mental health and emotional wellbeing, relationships and social connection, and daily life functioning. Participants spoke about drinking alcohol to improve their poor mental health and emotional wellbeing. The theme of mental health and emotional wellbeing was important to participants, and they highlighted this further by expressing their goals and desires for their mental health and emotional wellbeing. The positive role alcohol potentially played in the mental health and wellbeing of participants was further demonstrated when participants spoke about how their mental health and emotional wellbeing suffered when they entered

recovery from PAU. Interestingly, this was also the case for some AFMs who noted how their mental health and emotional wellbeing suffered when their family member with PAU entered recovery.

Alcohol also played a potentially positive role in peoples' QoL in terms of their relationships and social connection. For instance, participants spoke about using alcohol to connect with others or alleviate social disconnection. The theme of relationships and social connection was also fundamental to participants, and again they further demonstrated this by highlighting their goals and desires for their relationships. There was further evidence of the potentially positive role of alcohol in participants' relationships when participants spoke about how recovery from PAU could lead to losing relationships and connections with others. AFMs also spoke about the negative impact their loved one's recovery from PAU could potentially have on their relationships, which further demonstrated alcohol's potentially positive role.

Finally, concerning the potentially positive role alcohol could play in people's QoL, participants spoke about drinking alcohol to deal with daily life and their general life problems. While this set of findings does not negate the many negative effects of alcohol, it highlights the complex relationships with alcohol that were brought up in the study, which can help to explain the difficult recovery pathways faced by individuals affected.

7.2 Strengths of the Study

The following paragraphs will further highlight some of the strengths of the current study. These strengths will include some of the benefits of the qualitative research for this topic, the detail and depth of the interview data, empowering and giving a voice to those who may not

usually have the opportunity to tell their story, the value of getting different perspectives, developing positive partnerships with communities, and, finally, laying the groundwork for further quantitative research.

7.2.1 Benefits of a Qualitative Study/ Detail and Depth of Interview Data

Some of the strengths of this study relate to the fact that it was a qualitative study. Qualitative research can produce detailed depictions of people's experiences, opinions, and feelings, interpret the meaning of their actions, and holistically understand the human experience in specific settings (Denzin, 1989; Rahman, 2020). Quantitative measures alone may not tell the whole story of the issues affecting individuals or communities. Qualitative methods enable the exploration of people's subjective interpretations of life events, the personal meanings they create, and the underlying feelings and cognitions that can come from these (Banyard & Miller, 1998). Qualitative methods help us understand the "why" of human behaviour, the subjective meanings of people's experiences and specific behaviours, and enable us to tell "the rest of the story" regarding these issues (Banyard & Miller, 1998). Participants in the current study shared their experiences using whatever words and metaphors they felt necessary and were unconstrained by the limitations of forced-choice answer categories of quantitative research, where people may have to reduce their experiences to fit into a range of predefined answer choices (Banyard & Miller, 1998). The benefit of having the liberty to express oneself freely was evident in the current study, as participants spoke willingly and at length about their meaning and experience of QoL. On many occasions, the interviews went significantly over the suggested timeframe of one hour, demonstrating further how comfortable and willing participants were to talk about their lives.

Another strength of the study was the detail and depth of the interview data. Semi-structured interviews were used to investigate the participants' meaning and experience of QoL and explore their underlying values, beliefs and assumptions. Interviewing in research is an observational approach to developing empirical knowledge or theoretical models, and language is the data of interviews (Patton, 1990; Padgett, 1998). Personal narratives from interviews have importance in research because of the expressive power of language to describe, explain, evaluate, and provide meaning (Hammersley & Atkinson, 1995; Legard, Keegan, & Ward, 2003). The data from interviews in this study enabled me to capture the complexity of people's feelings, thoughts, and perceptions, as what an individual says in an interview can uncover their mental world and the logic they bring to their experiences (Goodman, 2001). Hence, a notable strength of the current study was the detailed and deep depiction of the experiences of individuals with PAU, and their families, concerning their QOL. In this regard, participants spoke at length about personal and private aspects of their lives and issues and matters that only a therapist usually might hear. However, all participants acknowledged the importance of research such as the current study and, therefore, were very forthcoming, open and honest with their stories. On a couple of occasions, participants felt awkward after the interview and felt maybe they had overshared or spoken too candidly about their lives. Therefore, in these instances, it was essential to keep in touch and check in with key workers to ensure that participants knew that their privacy and identity were protected and that they had shared their stories in a non-judgemental setting.

7.2.2 Giving a Voice to Participants

Another strength of the current study was how it provided an opportunity for a particular group of individuals to speak about their life and experiences, people who would usually not get to do so. This point is especially true for the family members impacted by PAU, who are

part of a very under-researched group. By their very nature, qualitative research methods document the "voices" of participants (Banyard & Miller, 1998). Hartman (1990) stated that investigating peoples' worlds through interviews "gives voice" to their life experiences. From both phases of the current study, many participants highlighted their satisfaction at being given time and space to tell their stories, representing a feeling of empowerment. From the very beginning of the study, this notion of empowerment for participants was prioritised, fostered, and encouraged. Mishler (1986) stated:

The effort to empower respondents and the study of their responses as narratives are closely linked. They are connected through the assumption...that one of the significant ways through which individuals make sense of and give meaning to their experiences is to organise them in a narrative form...various attempts to restructure the interviewee-interviewer relationship so as to empower respondents are designed to encourage them to find and speak in their own "voices" (p. 118).

The interviews in the current study effectively explored the sensitive and complex phenomena of PAU and PAU in the family and allowed participants to raise the issues that mattered most to them. The interviews generated a high level of detail as participants had the opportunity to speak about their actual experiences of quality of life related to living with PAU or having a family member with PAU, which provided the opportunity for an in-depth understanding of these particular issues. I viewed participants as experts in the area and always shifted authority away from myself, which seemed to help participants feel at ease. This step encouraged participants to open up and speak more about themselves throughout the interviews, which seemed to produce more credible and trustworthy data concerning their issues around PAU and PAU in the family (Goodman, 2001). Hence, another strength of the

current study was that it gave a voice to those who may not usually get the opportunity and empowered them to tell their stories on the sensitive and complex topic of PAU.

7.2.3 Value of Getting Different Perspectives

Another strength of the current study concerned the value of getting different perspectives about PAU and QoL. When it comes to measuring QoL in the area of PAU, research has primarily focused on the individual with the alcohol problem (Drummond, 1990; Malet et al., 2006; Luquiens et al., 2015). This may be why most of the support and treatment in the area of PAU in Ireland focuses on these individuals (Western Region Drugs Task Force, 2015; Alcohol Action Ireland, 2021). However, as we have seen, PAU can negatively impact many others and not just the individual. Therefore, it was essential to get a different perspective on this.

Problem alcohol use can have a range of adverse effects on the family (Orford et al., 2010; Joolaei et al., 2014), and, at times, there can be severe consequences for a family's safety and wellbeing (Butler & Bauld, 2005; Oreo & Ozgul, 2007; Yuen & Toumbourou, 2008; Hope, 2014; AAI, 2016). Therefore, AFMs were also invited to give their perspectives in the current study. While the individual with PAU's perspective is valid, by only focusing on this one perspective, we may formulate an incomplete view of the true nature of PAU and its association with the QoL of the individual and those who are close to them. Therefore, gaining the perspective of family members impacted by PAU is essential as their perspective is just as valid as those with PAU. This point is especially true in regards to treatment because if researchers only view an issue from one perspective, they may not acquire a thorough understanding of the entire problem, which may result in support and treatment programs addressing issues with limited knowledge and hindering their attempts to uncover a

solution that takes the needs of everyone affected into consideration. Recent research by the Western Region Drugs Task Force (2015) and Alcohol Action Ireland (2021) supports the issue regarded by researchers and practitioners working in PAU and its impact on the family in Ireland that more treatment and supports are needed for the family. Viewing issues around PAU and QoL from multiple perspectives should benefit those making the decisions around PAU support and treatment to make better-informed choices (Hall & Davis, 2007).

7.2.4 Developing Partnerships with Communities

Another strength of the study was that it promoted effective community-academic partnerships through direct communication and feedback to contribute to the improvement of services for those impacted by PAU. The study began as an alcohol treatment programme evaluation and, from the beginning, the thoughts and opinions of community stakeholders were put to the forefront and prioritised. This approach was pertinent as research has found that the perceptions and experiences of community partners in community-academic partnerships are essential to inform the further development and evolution of these partnerships (Wolff & Maurana, 2001). In their study, Wolff and Maurana (2001) reported that themes such as the creation and nurturing of trust, respect for a community's knowledge, community-defined and prioritised needs and goals, and continuous flexibility, compromise and feedback, were perceived by community respondents to influence the effectiveness of community-academic partnerships strongly. From the beginning of the study, these factors were considered and attended to by keeping frequent and open communication with community partners and continuously looking for feedback from them. These actions established trust, promoted flexibility and compromise, and showed respect for the community stakeholders' knowledge, needs and goals.

7.2.5 Laying the Groundwork for Quantitative Research

Qualitative methods can improve quantitative research (Banyard & Miller, 1998), so a further strength of this qualitative study is that it sets the foundations for further quantitative studies and the development of culturally anchored quantitative methods and measures. By utilising qualitative methods such as interviews during the initial stages of research in these communities, other researchers in the area can identify contextually important variables while avoiding inappropriate norms and constructs derivative of other populations (Banyard & Miller, 1998).

The literature shows that in quantitative research, many general, health-related and alcohol-specific QoL scales include the same or similar domains to those reported in the current study's findings. For instance, general QoL scales such as the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) (Endicott et al., 1993) include domains related to mental health and emotional wellbeing, relationships and social connectedness, and daily life functioning. Other general QoL scales, such as the WHOQOL-100 (WHOQOL Group, 1994) and the WHOQOL-BREF (WHO, 1998), include domains that centre around psychological or emotional health and relationships and social connection. Health-related QoL scales such as the SF36 (Ware & Sherbourne, 1992) includes domains related to mental health and emotional wellbeing, daily life functioning, and social functioning. The EuroQol (EQ-5D) (EuroQol Group, 1990) includes mental health, emotional wellbeing, and daily functioning domains. In terms of addiction and alcohol-specific scales related to QoL, the 9-item Alcohol Index QoL (AlQoL9) (Malet et al., 2006) includes domains related to mental health and emotional wellbeing, relationships and social connection, and daily life functioning, while the Alcohol Problems Questionnaire (APQ) (Drummond, 1990), the Addiction Severity Index (ASI) (McLellan et al., 1992), and the Alcohol Quality of Life Scale (AQoLS) (Luquiens et

al., 2015) includes domains related to mental health and emotional wellbeing, and relationships and social connection. Although the above scales include domains related to the themes generated in the current study, they may not be suitable for individuals with PAU. For instance, these scales may omit essential factors such as the purpose alcohol has in the individual's life, trauma, the seemingly strong association with suicide and self-harm, and the intense emotional comedowns or all-time lows or rock bottoms due to PAU.

This study provides other researchers in the area with conceptual roadmaps that they can use for previously uncharted territory, i.e., QoL scales for family members impacted by PAU. Although there is research out there on the impact of PAU on the family (Orford et al., 2010; Joolae et al., 2014), there is little research on QoL measures specific to family members impacted by PAU. Therefore, this group has limited or no culturally informed or standardised research instruments. A scale for AFMs would benefit from focusing on specific aspects of the individual's mental health and emotional wellbeing, such as shame, worry and anxiety. There should also be a specific focus on trauma, abuse, and neglect. Other important aspects to focus on within a QoL scale for AFMs would be perceived social support, boundaries, outlook, ability to express oneself, and the burden of role and responsibility. Finally, it may also be beneficial to distinguish AFMs concerning their relationship with the family member with PAU.

7.3 Study Implications

This study set out to investigate the meaning and experience of QoL for individuals with PAU and the family members of individuals with PAU. Findings from this study have implications for the area of PAU research and those who are impacted directly and indirectly by PAU. The following paragraphs discuss the implications of the research, the conclusions

taken from the findings, and how they may be meaningful for policy, practice, theory, and subsequent research.

7.3.1 Implications for Policymakers

In light of the current pattern of findings, policymakers can more explicitly acknowledge and more deeply understand that and how PAU affects the individual and those around them.

Therefore, with that, they should provide more opportunities and support for PAU treatment workers in developing and improving professional practice in PAU treatment and support for both the individual and those close to them. In particular, there should be more of a focus on providing opportunities and support for PAU treatment workers in their treatment and support of children impacted by FPAU in areas like children's mental health, social and emotional support for children, and dealing with children's identity issues and the burden of role and responsibility that they carry due to FPAU.

Policymakers need to improve support for children impacted by FPAU in their daily lives. Programmes such as the Hidden Harm Practice Guide developed by the HSE and Tusla (2019), and Meitheal, developed by Tusla (2017), are welcomed as early intervention programmes to help children impacted by PAU. However, it may also be helpful for those working with children, such as school teachers or sports coaches, to have the adequate training and awareness to provide children impacted by PAU with the emotional support they need, without the need to call for an intervention that would include many agencies and might be overwhelming or intimidating for a child who is going through difficulties. This idea refers to the concept of the child having a positive bond with at least one caring adult, who can play a significant role as a protective factor for the child and can offer them a safe place or respite from issues related to FPAU (Bancroft, 2004; Osbourne & Berger, 2009;

Velleman & Templeton, 2016). This issue was important for some participants when they spoke about their childhood in the current study. They felt they just needed one person to open up to about their problems at home and who could assure them that it was ok and not their fault. One simple conversation may be all that is needed for the child not to feel alone. However, if needed, these workers could refer the issue to the appropriate supports, i.e. Meitheal.

In October 2021, Maynooth University and Alcohol Action Ireland held an event called “Hope and Healing” to highlight the need for trauma-informed practice in education settings and to look at developing a framework of what trauma-informed practice might involve in an Irish context. Based on the current study's findings, implementing such programs and providing those who work directly with children with the necessary training could benefit children whom PAU impacts. Furthermore, in 2011, an organisation called “Operation Encompass” was set up in the UK. This organisation is a “police and education early information safeguarding partnership enabling schools to offer immediate support to children experiencing domestic abuse” (Operation Encompass, 2022). Programmes such as this may be helpful as a blueprint when developing school support programs for children whom FPAU impacts.

Policymakers should also acknowledge the perceived lack of support for family members affected by PAU, especially concerning a lack of community or environmental support and the issues in our society around drinking culture and the normalisation of problem drinking in Ireland. Suppose policymakers considered such matters from a policy viewpoint through, for example, school educational programs about alcohol and its potential impact on the individual and the family, the impact of PAU on the individual and the family

as a whole might become more apparent and accepted within Irish society. These steps may then lead to less stigma towards individuals with PAU and their families and more supportive communities. There are already some educational programs for children around alcohol use, such as *Know the Score* (HSE, 2022) and *Healthy Choices* (HSE, 2022). However, these programs seem to focus more on the child's health and relationship with alcohol and other drugs and do not seem to focus too much on how FPAU can impact the child or the family as a whole. Therefore, it may be helpful to develop an educational program that can educate children about the potential impact of PAU on the family and introduce it to children at a younger age, for example, ages 10-12, before they enter adolescence when they may form their own relationships with and attitudes towards alcohol.

There is a resource in the UK called *Rory* aimed at primary school children (Alcohol Focus Scotland, 2022). This resource centres on a story about a dog named Rory who can't understand why his owner is acting a certain way. Rory feels that it is his fault when his owner is angry or does not look after him. However, he then learns that his owner's behaviour is not his fault and that it is because his owner is drinking too much alcohol. A resource such as this may be practical in Ireland to help children who FPAU impacts realise that their parents' behaviours are not their fault and that they are not on their own with their problem related to FPAU.

Policymakers need to listen to those impacted by PAU and provide them with the opportunity to influence and contribute to all levels of policymaking. Over the last couple of years, Alcohol Action Ireland launched an initiative called Silent Voices (Alcohol Action Ireland & Health Research Board, 2022), which aims to influence policy by giving a voice to adult children of alcoholics experiences and providing a platform for those who have lived

through the trauma of parental PAU, so that others who may be experiencing similar difficulties may not feel alone. This year, Alcohol Action Ireland have also decided to bring an advocate for PAU onto their board to try and help guide them in their aims for policy change around PAU in Ireland (J. Hough, Alcohol Action Ireland, personal communication, 3 February 2022). Much health literature supports the use of patient-centred care and patient-reported experience measures to monitor the provision of patient-centred care (Hinsley, Kelly, & Davis, 2019). However, there is a dearth of research into the effectiveness of patient-centred care and patient-reported experience measures in the area of treating PAU (Hinsley, Kelly, & Davis, 2019; Davis et al., 2020). This level of validation and empowerment could provide those impacted by PAU with a representation at the highest level and, finally, give them a voice that seems to have been overlooked for so long. These measures could be especially beneficial for children impacted by FPAU, who appear to have less opportunity to voice their thoughts, concerns, or troubles.

7.3.2 Practical Implications for Professionals and Service Providers

There are several important possibilities regarding how these findings can be assimilated into professional practice by professionals across relevant services. One key factor is that those working within PAU treatment and support should redesign their regular treatment programs to include the AFMs. Some treatment programs, such as the Rutland Centre, Coolmine and Keltoi, include some family support structures. However, there is still a need for the further development and practice of evidence-based family programs, as much of the support is based on information and referral options, as opposed to the family being part of the treatment alongside the individual with PAU (Western Region Drug Task Force, 2015; Department of Health, 2021; Alcohol Action Ireland, 2021; 2022). The Rise Foundation is one registered charity in Ireland that focuses solely on the recovery of family members

impacted by addiction, whether the individual with the alcohol problem is in recovery or not (The Rise Foundation, 2022). However, their services seem restricted throughout Ireland due to a lack of funding (B. Allen, The Rise Foundation, personal communication, 25 April 2022).

Including the family, and giving them more importance, within alcohol treatment designs, would benefit both the AFMs and the individual with the alcohol problem (Copello et al., 2006; 2010). In addition, there should be more of a focus on children and how FPAU impacts them when redesigning treatment programs to include the family. It would be beneficial if those working in PAU treatment were to acknowledge the children of those in treatment and ensure that they get the necessary support. Interventions for children might include educational programs on PAU and the family. As mentioned previously, some educational programmes such as *Know the Score* (HSE, 2022) and *Healthy Choices* (HSE, 2022) teach teenagers about the potential negative impact of alcohol. However, it may be beneficial to have educational programmes that teach younger children about PAU and its potential impact on them and their families. Furthermore, it may be beneficial to provide group or one-to-one therapy to children affected by PAU or to connect them with another positive, caring adult in their life who can acknowledge what they are going through and offer support.

Furthermore, if the child and those working within the treatment process feel it is safe to do so, it may be beneficial to have family therapy, where the child can express themselves to their family member with the alcohol problem. Treatment for children might also include helping them with their mental health and emotional wellbeing making sure that they stay connected with family and friends whom they trust and feel safe with dealing with issues

around their identity and the burden of responsibility they carry from a young age. If the above steps are taken by those working in PAU treatment, family members may begin to feel that there is support for them out there. Through improved treatment options, they may learn about PAU and what is happening for them, which could help them gain the confidence to speak more openly to others about their issues, helping to lessen the stigma they might feel around it.

Because alcohol potentially plays a positive role in the QoL of people affected, one of the most important implications for practice would be examining this and using the findings to tailor treatment to the individual with PAU. For example, treatment facilitators should determine the nature of alcohol's role in the individual's QoL and whether it serves a positive purpose. This purpose may include drinking to help deal with mental health and emotional wellbeing, drinking to connect with others or to alleviate social disconnection, or drinking to function in daily life. If treatment facilitators can narrow these factors down, it may be easier to tailor treatment for the individual. For example, if someone drinks to connect with others and gives up drinking during treatment, they may be left with a large void in their life. Therefore, treatment facilitators could look for other ways for these individuals to connect with others more healthily, such as spending time with loved ones or participating in sports or hobbies as part of their tailored treatment program.

7.3.3 Theoretical Implications for QoL Measurement

This study also has implications for how researchers might think about alcohol-related QoL. The findings in this study should be noted concerning QoL measurement in individuals with PAU. Addiction and alcohol-specific scales related to QoL such as the Alcohol Problems Questionnaire (APQ) (Drummond, 1990), the 11-item Alcohol-Related Problems

Questionnaire (ARPQ) (Chick, Rund & Gilbert, 1991), the Addiction Severity Index (ASI) (McLellan et al., 1992), the 9-item Alcohol Index QoL (AIQoL9) (Malet et al., 2006), and The Alcohol Quality of Life Scale (AQoLS) (Luquiens et al., 2015) include domains related to mental health and emotional wellbeing such as psychological health, mental health, psychiatric symptomatology, looking after self, and emotional impact, and domains related to relationships and social connection such as social functioning, and interpersonal relationships including friends, marriage and children. One alcohol-specific scale, the 9-item Alcohol Index QoL (AIQoL9; Malet et al., 2006), includes domains related to daily life functioning, for instance, physical functioning, role physical/ limitation, role emotional/ limitation, and vitality.

However, the current study suggests that further developments may be needed within alcohol-related QoL measurements to investigate alcohol's specific role in an individual's QoL or its purpose in their life. For instance, is the individual drinking to improve or self-medicate their mental health or emotional wellbeing issues, or are they drinking to connect with others or function in their daily lives? Current measures may also overlook the significance of factors related to PAU and the precedence given to them by participants in the current study, such as trauma, the potential for suicide and self-harm, intense emotional comedowns, and all-time lows or "rock bottoms" due to PAU. If factors such as these were considered and developed within alcohol-related QoL scales, treatment pathways for individuals with PAU might evolve and become more focused and effective.

Concerning family members of individuals with PAU, as there are no specific scales that measure their QoL specific to the impact of their family member's PAU, it may be helpful to incorporate the current study's findings into the design and development of such scales.

Although it could be argued that more general QoL scales may be suitable for AFMs (with no alcohol problem), the findings show that alcohol still seemed to have an influential and unique role in their lives. This issue should be noted when attempting to measure AFMs' QoL or developing a QoL scale for AFMs. A QoL scale for AFMs should also include significant factors such as shame, worry and anxiety, trauma, abuse, neglect, perceived social support, boundaries, outlook, ability to express oneself, and the burden of role and responsibility. It may also be beneficial to distinguish AFMs concerning their relationship with the family member with PAU, for instance, the distinction between being impacted by FPAU in childhood and being impacted by FPAU as an adult. Although the current study's findings may provide a valuable starting point for developing such a measure, there are some questions that may need to be considered when designing or developing a scale that measures the QoL of AFMs. For instance, why did family members' mental health and emotional wellbeing or relationships and social connection worsen when their family members were recovering from PAU? Moreover, what role was the problematic alcohol use playing in these associations?

However, researchers, policymakers and practitioners should also note that the solution to issues around measuring the QoL of individuals with PAU and AFMs may already exist in the form of individualised measures of QoL (see section 2.1.4, p. 41), which address an individual's specific concerns in contrast to external, potentially less individually relevant standards (Gallagher & Desmond, 2007).

7.3.4 Recommendations for Future Research

The current findings demonstrate the importance of future research on AFMs of individuals with PAU. If we understood this group better and the role that alcohol plays in their lives, it

could lead to the ability to directly measure their QoL, which could lead to faster and more effective treatment for them. A Boolean search within all the databases of academic search complete was conducted on the 18th of February 2022. When the words “alcohol” and “quality of life” were searched for in the title of English language peer-reviewed papers, there were 571 results. When the words “alcohol” and “quality of life”, and “family” were searched for in the title of English language peer-reviewed papers, there were only four results. When the words “alcohol” and “quality of life” were searched for in the abstract of English language peer-reviewed papers, there were 8,619 results. When the words “alcohol” and “quality of life”, and “family” were searched for in the abstract of English language peer-reviewed papers, there were only 726 results. These findings show us how research on the individual with the alcohol problem may be prioritised over research on AFMs.

As mentioned previously, participants in the current study emphasised their satisfaction at being given the time and space to tell their stories and, as people can make sense of and give meaning to their experiences by organising them in a narrative form (Mishler, 1986), it is essential to continue to do this with these particular research groups. Future qualitative studies in the area of PAU are also crucial because of the value of getting different perspectives when trying to understand the whole problem of PAU. Gaining this more comprehensive knowledge might help improve PAU treatment and support programs by giving them more focus on the broader problem of PAU and how it impacts many others and not just the individual with the alcohol problem.

Concerning future qualitative research in PAU, researchers should continue to give a voice to both individuals with PAU and AFMs. One particular perspective that could be researched in more detail in the future is the perspective of children living with FPAU. The

findings in the current study show that children seem to have difficulty having their voices heard when it comes to how PAU impacts them. Although the current study did not intend to investigate the meaning and experience of children impacted by PAU's QoL, the data still showed that FPAU impacted children's QoL in many ways. Therefore, future studies in this area would be necessary to give children their chance to truly voice how PAU impacts their life, with a particular focus on the burden of care and responsibility and issues around identity and self.

Future studies might also look more in-depth at the role alcohol can play in an individual's QoL and how it can potentially play a positive role in an individual's life, particularly around helping them deal with their mental health and emotional well-being and their relationships and social connection. One of the most important implications for future research from the current study is investigating alcohol's role in people's lives and their QoL and using these findings to tailor treatment to the individual and the family member. These investigations into alcohol's specific role in an individual's QoL could lead to developments within alcohol-related QoL measurements, leading to more focused and effective treatment programs. Future research should also design and develop alcohol-related QoL scales for family members.

This qualitative study can also help develop future quantitative research and expand quantitative methods and measures. While several QoL measures specific to PAU are available for individuals with PAU (Drummond, 1990; Malet et al., 2006; Luquiens et al., 2015), there are currently no specific measurements for AFMs. Therefore, future researchers should use qualitative studies such as this one to develop culturally informed or standardised research instruments for these groups. While there are some supports for the families out

there (e.g. The Rise Foundation, The Rutland Centre), there are no standardised QoL scales and no quick and easy way of measuring AFMs' QoL.

Family members in phase two were recruited over the internet using advertisements, resulting in potential sampling bias. Research shows that PAU can be associated with poverty (Setlalentoa et al., 2010; Tiwari, Srivastava & Kaushik, 2010) which may result in less access to computers or smartphones or being able to pay for internet access. Therefore, recruiting over the internet has the potential to overlook this group who may not have access to the internet. Also, age may be a factor in sampling bias as older adults are potentially less likely to access computers, the internet, or social media. Regarding these potential sampling biases, future studies may look to recruit family members whom FPAU impacts through different means instead of through the internet. For instance, recruiting family members through a treatment program similar to participants in phase one may be helpful. While there potentially may have been some sampling bias within the current study, this issue seemed to be offset because the data collected was rich and impactful.

Future studies might also investigate family members without the exclusion criteria of not having a problem with alcohol, which was included in the current study's sample criteria to distinguish these individuals from participants in phase one. Although these family members may then potentially be problem alcohol users themselves, due to the nature of PAU in the family and its cyclical nature down through the generations, it may be helpful to get this group of individuals' perspective. Future studies such as these may give researchers a more comprehensive and valid understanding of the broader impact of PAU on people's lives and their QoL. Furthermore, as discussed further below in the limitations section, the current study had issues around survivorship bias and social desirability bias. Therefore, future

qualitative researchers might investigate the narratives of individuals who are not in treatment or who have never entered treatment. There may also be a necessity for further qualitative research to investigate other sources of adversity of individuals with PAU or the family members of PAU, their protective factors, and their resilience.

7.4 Study Limitations

This study has some limitations, outlined in the following paragraphs. These limitations include the potential for sampling bias, including self-selection bias, exclusion bias, survivorships bias, and the role of the internet in recruitment. Study limitations also include the potential for participant bias, including social desirability bias, demand characteristics, and participant reactivity. The third limitation discussed focuses on the potential for over-identification with study participants. Finally, the discussion around the study's limitations will focus on how the study did not fully consider other sources of adversity for participants, potential protective factors in their lives, and participants' resilience.

7.4.1 Sampling Bias

One of the main limitations of the current study was the potential for sampling bias, which included self-selection bias, exclusion bias, survivorship bias, and sampling bias due to recruitment over the internet. Self-selection bias is based on the idea that, within voluntary participation, people who consent to be involved in research may be different from those who do not in ways that are not related to sampling criteria (Costigan & Cox, 2001). For instance, interviews may require extensive intimate self-disclosure; therefore, a qualitative study using interviews for data collection, such as the current study, may lead to a sample who are more open and honest, more patient and more interested in the research topic than the general

sample frame (Robinson, 2014). This issue may not have been as prominent for phase one of the study, as participants were recruited with the help of gatekeepers within their treatment programs. However, it may have been more of an issue for phase two, where participants were recruited over the internet. Furthermore, recruiting participants over the internet can skew a sample as specific groups of individuals may not have as much access to the internet (Robinson, 2014). There is not much that could be done to eliminate the potential of self-selection bias, as voluntary participation is central to good ethical practice. However, it is still essential to be aware of it and consider its potential influence on findings and generalisability. Furthermore, this potential bias is potentially offset because rich experiential data was collected in the interviews.

Another element of sampling bias that might have influenced the current study is exclusion bias. Exclusion bias, also known as attrition bias, refers to the various potential biases that can result from excluding particular individuals from a study and the subsequent analyses (Tierney & Stewart, 2005). For instance, for phase two of the current study, family members who had their own problems with alcohol were excluded from the sample. This exclusion is important to note as much literature shows that being impacted by FPAU can lead to addiction (Price & Emshoff, 1997; Park & Schepp, 2015). However, there was a strong argument for this exclusion criterion because if participants in phase 2 also had alcohol problems, then they were no longer “just family members”. Also, many participants in phase 1 grew up with PAU in their families; however, this was not an inclusion criterion for the current study.

Another aspect of sampling bias that could influence the current study was survivorship bias. Survivorship bias centres around the idea that individuals who came

through a particular selection process accurately represent a whole sample frame (Shermer, 2014). However, it is possible to accidentally ignore certain people who did not make it through a particular selection process. For instance, in the current study, all participants in phase one were actively participating in outpatient treatment programs for their alcohol use. Therefore, these individuals could be viewed as the "survivors", and individuals who are actively drinking and have never received treatment are being omitted from the research, therefore bringing about a sample bias.

7.4.2 Participant Bias

A second limitation of the current study was the potential for participant bias, which included social desirability bias, demand characteristics, and reactivity. Social desirability bias means underreporting socially undesirable attitudes and behaviours and over-reporting more desirable attributes (Latkin et al., 2017). This concept may have been an issue, especially in phase one, where participants may have provided socially desirable responses deliberately or unwittingly (Spector, 2004). For example, participants may have been less likely to share honestly about the true nature of the impact of their PAU on others and, while they did speak about such issues, they may have under-reported due to social desirability bias. However, it is difficult to see an obvious example of this when reading the transcripts, as the data is rich, and highlights many undesirable aspects of the behaviours of the participants in question and would seem difficult to "fake".

On the other hand, while confidentiality was assured to participants, given that participation in phase one occurred within a treatment context, it is conceivable that participants were less open and honest than they would have been in another context. For instance, at the beginning of one interview in phase one, a participant asked if their participation contributed to their

wish to get into residential treatment. If other participants similarly held this belief, it may have led to some social desirability bias within their responses. However, participants in both phases of the study did appear to be comfortable in the interview setting and seemed quite candid in their responses to the interview questions.

Demand characteristics describe specific cues in behavioural research that may inadvertently affect a person's response or behaviour in an interview or experiment (Allen, 2017). If researchers are not wary of them when proceeding with a study, demand characteristics can manifest in many ways and create bias in research due to the participants becoming aware of the purpose of the study (Allen, 2017). For instance, demand characteristics can occur due to cues in how the researcher behaves, which may indicate what the researcher expects to happen within the study. If participants pick up on these cues, they might change their responses or behaviours to comply with what they believe are the researcher's expectations of the study. They may also behave opposite to what they believe the researcher expects. All participants knew what the current study was about before interviews began, and there was no deception. However, this knowledge may have resulted in demand characteristics during the interviews. One aspect of demand characteristics that may have influenced the current study's findings is participant reactivity.

7.4.3 Over-identifying with Study Participants

A third limitation within the current study concerns the potential for the researcher to over-identify with study participants. Researcher over-identification can potentially influence the researcher's interpretation of qualitative research findings resulting in bias (Schonfeld & Mazzola, 2013). Due to the researchers' own experience as a family member impacted by addiction throughout his own life, there was a concern for the potential to observe more

wrongdoing in the individual with PAU than was warranted and more victimisation in the family members impacted by PAU than was justified. However, the researcher remained mindful of this potential bias throughout the study and maintained the findings to be accurate and objective despite the interpretative nature of the research. Although all interview questions were open-ended to avoid bias, the researcher noticed a few suggestive or implied questions or expressions while listening back or reading the interview transcripts. These occasional cases were considered and addressed during the coding and interpretation of the data, through memoing and during supervision.

7.4.4 Other Sources of Diversity, Protective Factors, and Resilience

Another limitation in the current study is that other sources of adversity may have played significant roles in some aspects of participants' quality of life, for example, in their mental health or daily life functioning. Although PAU was spoken about in a certain way as having specific impacts on participants' lives, there may have been other influential factors, such as the person's wider environment or the impact of poverty or social inequalities (Lapresa, Arizaleta & Rajmil, 2012; Li et al., 2021). Although participants spoke about such issues, there was much less emphasis on them than the role of alcohol within their QoL, possibly due to participants' knowledge of the PAU research topic. It is essential not to overlook such environmental factors and acknowledge that they may have also had a significant role in participants' behaviour and their meaning and experience of QoL.

On the other hand, there may have been positive qualities in participants' lives that may have received less emphasis due to the nature of the research focusing on problematic alcohol use, for example, protective factors or resilience. For instance, participants from phase one took part in outpatient treatment programs, while participants in phase two

answered social media advertisements to participate in the research. Why had participants sought out treatment, or why had participants sought to participate in the research? Was there anything different about these participants as opposed to individuals who may not have accessed treatment or would not like to speak about their experiences as family members impacted by PAU? What may have been overlooked here are potential protective factors that may have contributed to these particular traits in individuals. Furthermore, the resilience of participants should also be considered. Were participants in the current study more resilient than others? Was it their resilience that helped them enter treatment or have the courage to tell their story?

7.5 Reflecting on the PhD Process

The following paragraphs reflect my experiences of the PhD process, including my self-awareness around my personality, beliefs and values, feelings, qualities, abilities, limitations, and behaviours. The section reflects on some of the things I have learned and how I feel I have developed and improved as a researcher. These reflections include being an AFMs myself, learning from the interview process, imposter syndrome and gaining confidence as a qualitative researcher, and my mental health during the PhD process.

7.5.1 Being an Affected Family Member

From the beginning of the study to the end, I was worried that feelings or emotions I had that were related to my life experiences might hinder the direction of the research or bring about biases within it. During the study, there were times when I questioned these feelings and emotions and wondered if it was proper for me to be feeling the way I did. For instance, during phase one, there were times when I struggled with my patience towards participants. This issue did not appear to manifest so much during interviews but during transcription and

the subsequent analysis. I felt frustrated by some participants, and I felt my patience wearing thin at times, especially if they spoke for long periods without speaking on the topic of the study. At times during this process, I also felt feelings of anger. Interestingly, my feelings differed during the transcription and data analysis of interviews from phase two. During this part of the research, I felt that I had a lot more patience, and my feelings weren't of anger or frustration but empathy, understanding and some sadness.

Although these emotional shifts may have stemmed from learning and becoming comfortable with the qualitative process, reflecting further brought me back to the point that I was also affected by my family members' addictions, especially during my childhood and adolescence. It was difficult to detach myself from this matter during the research. Therefore, throughout the research process, I reflected on it, particularly in phase two, where I consistently saw my own story in many participants' stories, especially their childhoods.

While listening back to the recordings and subsequently transcribing and analysing them, I believe emotions were being stirred in me due to my memories from childhood and adolescence and how I felt other family members' addictions had impacted me. This issue was particularly apparent in phase one, where I was experiencing feelings of frustration and anger. However, once I became aware of these feelings and the triggering nature of the interview data, I began to understand these participants' points of view and empathised with them more. These experiences made me think deeply and reflect on how my different reactions to both sets of interviews taught me a lot about how my life experiences could interact with my research. Being aware of this helped me deal with my emotions and feelings much easier. I tried to stay aware of this as much as possible, noting down these feelings in writing, and discussing them with my supervisors. In the end, I believe that I was able to be

true to the participants and their experiences, while also acknowledging how this affected me. My own experiences brought me to do this research and, therefore, I do not think that it is possible or appropriate to eliminate these, but to acknowledge and work with them as described above.

7.5.2 Learning from the Interview Process

Another occurrence during the research process involved my experience during one particular interview with a participant during phase one. I found this interview particularly difficult, especially initially, as the participant seemed very defensive and on edge. The way they spoke at the beginning of the interview indicated they were angry. When I asked a question, they would respond defensively, and they had a slightly aggressive demeanour. It seemed to me that they resented being there. At times, they challenged my interview questions in a way that felt somewhat disdainful. The participant spoke disparagingly about university students several times but then highlighted that I was okay because I was an older student, which made me uneasy. I had already conducted some interviews, and they had all gone very smoothly; therefore, I was taken aback when this interview began the way it did. The initial response that I got from the participant put me on edge, though I did not feel unsafe. I felt my confidence diminish, and I started to question myself. However, I recovered control of my emotions, shifting my thoughts and feelings towards a more positive subjective state. I held my position as the interviewer and remained neutral, similar to how I had been in previous interviews. I also focused on the view that the interview participants are the experts within the qualitative process and that there was potentially valuable data to be recorded.

Things changed within the interview when I shifted my thoughts and feelings. The participant was angry and seemed to be slightly projecting this towards me; I was

comfortable with that now. Furthermore, as the interview proceeded, I realised that the participant seemed to have issues with those they perceived might be in a position of authority, for instance, their GP, their counsellor, or anyone else that worked in the area of treating and supporting those with PAU. So, I reflected, maybe they saw me as someone similar. The participant's behaviour and attitude also seemed to change after I became more comfortable with myself. They began to relax and started making jokes, and by the end of the interview, they told me that they had enjoyed the whole process and felt good after it. Of the 25 interviews I conducted, I feel like this interview was the most challenging, but it was also the interview where I learned the most as a qualitative researcher. I learnt not to take things personally if an interview is not going the way I expect and that there is always the chance that someone might project their issues onto you, especially when it comes to sensitive matters such as PAU and how it can impact someone's life.

7.5.3 Imposter Syndrome and Gaining Confidence as a Qualitative Researcher

As a young man, I never acquired formal third-level education. Hence, since returning to third-level education as a mature student, I have struggled with confidence in my academic abilities. I have also become familiar with the concept known as "imposter syndrome", where I can sometimes feel like I do not have the necessary skills or knowledge to succeed and that this will become apparent to everyone around me. These issues became particularly intense when I began my PhD journey. During my undergraduate degree in psychology, while I did struggle with confidence, I found it easier to deal with the academic process as each assignment had guidelines that I could follow. This process changed a lot when I progressed to PhD level, and as a result, I felt my confidence waned further. I relied a lot on my supervisors, who were terrific and very understanding during the process and always gave me valuable and insightful feedback. However, as the PhD progressed towards the final months

and particularly around the discussion chapter, it seemed that my supervisors began to take a step back so I could make decisions for myself. I felt worried and anxious at this time, and again, I struggled with my confidence. Looking back, I think this was essential for my growth and development as a qualitative researcher. It was a difficult time, and honestly, I did not believe I would be able to write my final chapters. It just didn't seem doable. Looking back, I can see how low my confidence was and how I was marred by imposter syndrome. This period was the most challenging of all during the PhD. I spoke about my difficulties to my family, friends, and primary supervisor, and then I took a week off to gather my thoughts. I realised that I had no other option but to tackle the discussion chapter, so I sat down and made a plan. I charted out all my findings and began to look at what I felt were the most important findings to write. After I did this, the writing became a lot easier and eventually, I got the chapter written. This process was a huge learning curve and helped me grow in confidence as a qualitative researcher.

7.6 Concluding Statement

In conclusion, the current study has contributed to a deeper understanding of the meaning and experience of QoL for individuals with PAU and the family members of individuals with PAU. Problem alcohol use profoundly impacts both groups of peoples' QoL. However, it was also seen in the current study that alcohol can have a purpose in people's lives concerning their QoL. For instance, when alcohol is removed, it does not necessarily mean the individual or family member's QoL will improve; therefore, ongoing treatment and support may be needed for both the individual and the family. The findings suggest that individuals with PAU may not value abstention as alcohol may have a specific purpose in their life (e.g. helping their mental health and emotional wellbeing or helping them "function" or connect with others.). As such, treatment programmes must be aware that abstention may not be

desirable for individuals with PAU. Instead, getting alcohol use down to "non-problematic" levels may be more beneficial. The findings also emphasise further considerations that need to be made in measuring QoL with individuals with PAU and their families, including consideration of traumatic events relating to childhood encounters with FPAU. Also, concerning the family, the study highlights a need for more structures and developments for family support, especially for children whom PAU profoundly impacts. Findings from phase 2 could be used as a template to abductively create a QoL scale for family members, as no such scale appears to exist. These findings and associated recommendations can contribute towards improving policy and practice and, ultimately, the lives of those affected by PAU in our societies.

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Appendices

Appendix A: Plain Language Statements

A.1 Plain Language Statement Phase One



Exploring the Meaning and Experience of Quality of Life among individuals with Problem Alcohol Use

Researcher: Eoghan Scott, PhD Student – School of Nursing and Human Sciences, DCU

Research Supervisors: Professor Anne Mathews & Dr Simon Dunne, School of Nursing and Human Sciences, DCU; Dr Malcolm Brady, DCU Business School

Plain Language Statement.

You have been asked to participate in a research project that is being undertaken as part of a PhD research project at Dublin City University. The Finglas Addiction Support Team, Ballymun Youth Action Project, and North Dublin Community Care Service all support this research while the Dublin City University Ethics Committee has approved it. This PhD is funded by a scholarship awarded to Prof Anne Matthews by the Programme for Health Service Improvement of the Health Service Executive (HSE); however, the topic and study protocol has not been chosen by the HSE. Please read the following information, and if you have any questions regarding the study, please contact the named researchers.

It is documented that alcohol use can affect many people and is a big issue in Ireland. This study aims to understand what Quality of Life (QoL) means to individuals with problem alcohol use living in Dublin Ireland, and how these individuals experience QoL in their daily lives. Your participation in this study is valuable as the data you provide may be used to develop best practice for the treatment of problem alcohol use in Ireland, and tailor treatment to the specific needs of those living with problem alcohol use, by informing the measurement and consideration of QoL in alcohol treatment programs in Ireland. It could also potentially have implications for policy and funding. If you decide to take part in this research, you will be asked to spare roughly 1 hour to take part in an interview. The interview will focus on your understanding of QoL and how you think alcohol has

affected it. You will also be asked if you have been previously treated for problem alcohol use. With your permission, the interviews will be audio-recorded.

Some potential risks to participants may include unpleasant feelings, emotions, or traumas being triggered by interview questions. However, the interview questions will not be deliberately intrusive, and the researcher will make every effort to ensure that participants feel comfortable and safe during the interview. If, however, you do feel like you have become upset or distressed in any way, the researcher will make sure to connect you in with your key-workers or other clinical support staff that you feel comfortable with. You will also be given a sheet with telephone numbers of different organisations that may be of use if you feel distressed in any way. You can withdraw your participation from the study at any time up until the production of the final report. After data is written into the final report it may not be possible to remove your data; however, please be reminded that your data will always remain unidentifiable and anonymous. If you do decide to withdraw from the study, you will not have to give any reasons or explanations as to why. The researcher will make sure that participants anonymity and confidentiality is respected at all times and all data will be de-identified, with false names being used in any written material arising from the analysis. It is important to note however that confidentiality can never be absolute. Such limits are necessary if a strong belief or evidence exists that there is a serious risk of harm or danger to you or another individual, this will need to be brought to the supervisory team/ relevant management structure, and an appropriate course of action decided. These limits may relate to concerns for child protection, self-harm, suicidal intent or criminal activity. This study is also required to comply with legislation, and if the research team is ordered by a court of law to submit a report or is subpoenaed to give evidence, then the requested information must be shared with the courts.

The researcher verifies that only direct quotes will be used in the study and that these quotes will only be used in the context that was intended by the participant. The results of this research will be presented as part of a PhD study in DCU. The results may also be presented at national/ international conferences and submitted to academic journals for publication. As special category personal data is being collected and analysed, researchers will make sure at all times to comply with General Data Protection Regulations (GDPR). All hard copies of the information you provide, including consent forms, will be stored in a locked cabinet in a locked office at Dublin City University. Your information will be kept safe and secure and treated with strict confidence. Your personal details and views will not be revealed to anyone outside of the study team, and your name will not be identified in any reports or publications resulting from the study. All of the electronic interview transcripts and audio files will be stored securely on an approved password-protected Google Drive. No audio recordings will be played in any public forum. All data will be kept for up to five years following completion of the study. After this period, research supervisors will delete all electronic and audio data files and will shred paper records. The Research Supervisor/ Principal Investigator will undertake data destruction after the storage period in line with DCU research

policies. Personal feedback will not be provided to participants. However, a one-page summary of the study will be made available following completion of the study to those who make contact with the research team.

If you have any questions about the study or wish to raise an issue that you have with the study, its content or methods, please contact: eoghan.scott4@mail.dcu.ie, anne.matthews@dcu.ie, rec@dcu.ie

A.2 Plain Language Statement Phase Two



Exploring the Meaning and Experience of Quality of Life among adult family members of individuals with Problem Alcohol Use

Researcher: Eoghan Scott, PhD Student – School of Nursing, Psychotherapy and Community Health, Dublin City University

Research Supervisors: Professor Anne Matthews, Dr Simon Dunne & Dr Malcolm Brady, DCU

Plain Language Statement

What is the study about?

You have been asked to participate in a research project that is being undertaken as part of a PhD research project at Dublin City University. The Finglas Addiction Support Team, Ballymun Youth Action Project, and North Dublin Community Care Service all support this research while the Dublin City University Ethics Committee has approved it. This PhD is funded by a scholarship awarded to Prof Anne Matthews by the Programme for Health Service Improvement of the Health Service Executive (HSE); however, the topic and study protocol has not been chosen by the HSE. Please read the following information, and if you have any questions regarding the study, please contact the named researchers.

Problem alcohol use is a significant problem in Ireland and can have a profoundly negative impact on the quality of life of not only the individual with problem alcohol use but also family members who are affected by it. Alcohol Ireland reported that 72% of the Irish population believed that they knew someone who consumed alcohol excessively. Moreover, 42% of these individuals stated that person to be a member of their own family.

This study aims to understand what Quality of Life (QoL) means to adult family members of individuals (over 18) with problem alcohol use living in Dublin, Ireland, and how these family members experience QoL in their daily lives. Your participation in this study is valuable as the data you provide may be used to develop best practice for the treatment of problem alcohol use and its impact on family members of individuals with problem alcohol use in Ireland. It may help tailor treatment to the specific needs of affected family members of problem alcohol use, by informing the measurement and consideration of QoL in alcohol treatment programs in Ireland. It could also potentially have implications for policy and funding.

What do I have to do?

If you decide to take part in this research, you will be asked to spare up to 1 hour to take part in an interview. The interview will focus on your understanding of Quality of Life and how you think your adult family member's problem alcohol use has affected it. You will also be asked if you have ever accessed support or family services previously. Interviews will take place remotely either by phone or video call on telecommunications applications. If you wish to participate in an interview via a video call, we are offering you the option to do so using Facetime, Signal or Zoom. Both FaceTime and Signal offer end-to-end encryption services (i.e. it is not possible that someone other than the individuals in the conversation could access the information) and are very secure. As such, we recommend selecting one of these options for video call. However, if you do not have access to either of these applications, it is also possible to participate in the interview via Zoom. If Zoom is selected, all available security features will be employed for the interview process, but it should be noted that this application does not offer end-to-end encryption (i.e. it is possible that someone other than the individuals in the conversation could access the information), and thus is not as secure as FaceTime or Signal. Remember, you may also participate in the interview over the telephone if you prefer. With your permission, the interviews will be audio-recorded. Video of the interviews will not be recorded.

What are the risks involved in the study?

Some potential risks to participants may include unpleasant feelings or emotions being triggered by interview questions. However, the interview questions will not be deliberately intrusive, and the researcher will make every effort to ensure that participants feel comfortable and safe during the interview. If, however, you do feel like you have become upset or distressed in any way, the researcher will make sure to connect you in with organisations and counselling services that can offer you support. You will be provided with telephone numbers of these different organisations and counselling services. You can withdraw your participation from the study at any time up until the production of the final report. After data is written into the final report it may not be possible to remove your data; however, please be reminded that your data will always remain unidentifiable and anonymous. If you do decide to withdraw from the study, you will not have to give any reasons or explanations as to why.

Confidentiality and Data Protection

The researcher will make sure that participants' confidentiality is respected at all times and all data will be de-identified, with false names being used in any written material arising from the analysis. It is important to note however that confidentiality can never be absolute. Such limits are necessary if a strong belief or evidence exists that there is a serious risk of harm or danger to you or another

individual, this will need to be brought to the supervisory team/ relevant management structure, and an appropriate course of action decided. These limits may relate to concerns for child protection, self-harm, suicidal intent or criminal activity. This study is also required to comply with legislation, and if the research team is ordered by a court of law to submit a report or is subpoenaed to give evidence, then the requested information must be shared with the courts. The researcher verifies that only direct quotes will be used in the study and that these quotes will only be used in the context that was intended by the participant.

The results of this research will be presented as part of a PhD study in DCU. The results may also be presented at national/ international conferences and submitted to academic journals for publication. As special category personal data is being collected and analysed, researchers will make sure at all times to comply with General Data Protection Regulations (GDPR). All hard copies of the information you provide, including consent forms, will be stored in a locked cabinet in a locked office at Dublin City University. Your information will be kept safe and secure and treated with strict confidence. Your personal details and views will not be revealed to anyone outside of the study team, and your name will not be identified in any reports or publications resulting from the study. All of the electronic interview transcripts and audio files will be stored securely on an approved password-protected Google Drive. No audio recordings will be played in any public forum. All data will be kept for up to five years following completion and award of the PhD study. After this period, research supervisors will delete all electronic and audio data files and will shred any paper records. The Research Supervisor/ Principal Investigator will undertake data destruction after the storage period in line with DCU research policies. Personal feedback will not be provided to participants. However, a one-page summary of the study will be made available following completion of the study to those who make contact with the research team.

If you have any questions about the study or wish to raise an issue that you have with the study, its content or methods, please contact: eoghan.scott4@mail.dcu.ie, anne.matthews@dcu.ie, DCU Research Ethics Committee at rec@dcu.ie

Appendix B: Consent Forms

B.1 Consent Form Phase One



Exploring the Meaning and Experience of Quality of Life among individuals with Problem Alcohol Use

Researcher: Eoghan Scott, PhD Student – Dublin City University

Research Supervisor: Professor Anne Mathews, Dr Malcolm Brady, Dr Simon Dunne, Dublin City University

Participant Consent Form

By ticking the boxes on this page, you are actively agreeing to participate in the study, which is being conducted as part of a PhD research project.

The following statements reflect the criteria for consent to participate.

Please Circle “Yes” or “No” to each of the following questions to show whether or not you consent (agree) to the various parts of the study.

	Yes OR No
I agree to take part in this study on the Meaning and Experience of Quality of Life among individuals with problem alcohol use and I identify that I have a problem with alcohol use	Yes / No
I have read and understand the information sheet, have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	Yes / No
<i>I confirm that I am eligible to participate for the following reasons:</i> <ul style="list-style-type: none">▪ I am at least 18 years of age.▪ I am in a position to give informed consent and have a sufficient level of spoken English to participate.	Yes / No Yes / No
<i>I understand that:</i> <ul style="list-style-type: none">▪ My participation is entirely voluntary, and I am free to leave the study up until the report is written up, without giving a reason. This will not affect my rights or supportive care in any way.▪ All information about me, or my family, will be protected by the principles of confidentiality and both national and EU Data Protection Legislation.	Yes / No Yes / No
<i>I give permission for the research team to:</i> <ul style="list-style-type: none">▪ Audio-record the interview.▪ Store my interview data confidentially (i.e. separate to my name and address) for up to 5 years after the end of the study.▪ Contact me at a later date to offer further opportunities to participate in additional research	Yes / No Yes / No Yes / No

Name: _____ Tel: _____
Name and phone contact of participant (block caps)

Signature

Date

Name of researcher (block caps)

Signature

Date

B.2 Consent Form Phase Two



Exploring the Meaning and Experience of Quality of Life among adult family members of individuals with Problem Alcohol Use

Researcher: Eoghan Scott, PhD Student – Dublin City University

Research Supervisor: Professor Anne Mathews, Dr Malcolm Brady, Dr Simon Dunne, Dublin City University

By ticking the boxes on this page, you are actively agreeing to participate in the study, which is being conducted as part of a PhD research project. The following statements reflect the criteria for consent to participate. Please Circle “Yes” or “No” to each of the following questions to show whether or not you consent (agree) to the various parts of the study.

	Yes or No
I agree to take part in this study on the Meaning and Experience of Quality of Life among family members of individuals with problem alcohol use	Yes / No
I have read and understand the information sheet, have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily	Yes / No
I confirm that I am eligible to participate for the following reasons:	
I am at least 18 years of age.	Yes / No
I am in a position to give informed consent and have a sufficient level of spoken English to participate.	Yes / No
I do not have, or ever had, a problem with alcohol or other drugs, and I have never been in treatment for alcohol or other drugs.	Yes / No
I understand that:	
My participation is entirely voluntary, and I am free to leave the study up until the report is written up, without giving a reason. This will not affect my rights or supportive care in any way.	Yes / No
All information about me, or my family, will be protected by the principles of confidentiality and both national and EU Data Protection Legislation.	Yes / No
I give permission for the research team to:	
Audio-record the interview.	Yes / No
Store my interview data confidentially (i.e. separate to my personal data) for up to 5 years after the end of the study	Yes / No
Contact me at a later date to offer further opportunities to participate in additional research	Yes / No
I understand that:	
The Zoom application does not offer end-to-end encryption (i.e. it is possible that someone other than the individuals in the conversation could access the information) and it is not as secure as either FaceTime or Signal, but I would still like to use this application for my interview (Note: this question will only be included where Zoom is selected).	Yes / No

Name:..... Tel:.....
 Name and phone contact of participant (block caps) Signature Date

Name:..... Tel:.....
 Name of researcher (block caps) Signature Date

Appendix C: Social Media Advert



Research Participants Invited

We are currently seeking male and female participants over the age of 18, who are family members of someone (over 18) with a problem with alcohol use, to take part in a study that will explore the meaning and experience of their own Quality of Life.

If you are interested in taking part, you will be asked to participate in an interview. The interview will take place at FAST/ YAP/ North Dublin Community Care Services at a time that suits you and will last for approximately 1 hour.

The study is completely voluntary and confidential. Participants can withdraw their participation at any time without explanation.

For more information, please contact Eoghan:

Email: eoghan.scott4@mail.dcu.ie

Eoghan Scott,
PhD Candidate,
School of Nursing, Psychotherapy and Community Health,
Dublin City University,
Glasnevin,
Dublin 9

Appendix D: Interview Guides

D.1 Interview Guides Phase One

Section 1 – Alcohol Use and Alcohol Treatment

1. Tell me about your alcohol use.

(Prompts if needed)

- i. How much do you drink roughly?
- ii. When/ how often do you drink?
- iii. Is there a pattern to your drinking? (Alone, socially, binge, regular daily?)

2. At what point did you first realise that alcohol was a problem for you?

3. Tell me about how you think it got to that point? or Why do you think it became such a problem?

4. Tell me about your experiences of treatment for alcohol use, including any previous treatment and current treatment

(Prompts if needed)

- i. Is this your first-time seeking help for alcohol use Y/N
 1. If no, how many previous times have you sought help
 2. What help? AA or other Group Support, Rehab, Outpatient, Hospital Detox
 3. Tell me more about your own experience of treatment program X (Pros/ Cons)
 4. Tell me how you think your alcohol use may have affected any previous or current treatment
 5. (How many treatment sessions a week do you have in the current treatment)

5. If any, tell me about any other substances you use besides alcohol

6. Tell me about your experiences of any other treatment for any other substances

- a. Have you had previous treatment Y/N
 - i. If yes, how many previous times have you sought help
 1. Group Support, Rehab, Outpatient, Hospital Detox
 - ii. Tell me more about your own experience of treatment program X (Pros/ Cons)
 - iii. Tell me how you think your substance use may have affected any previous treatment

7. If any, tell me about any other addictive behaviours that may have a negative effect on your life?

8. Tell me about your experiences of any other treatment you have had for any other problem behaviours

- a. Have you had previous treatment Y/N
 - i. If yes, how many previous times have you sought help
 1. Group Support, Rehab, Outpatient, Hospital Detox
 - ii. Tell me more about your own experience of treatment program X (Pros/ Cons)
 - iii. Tell me how you think your substance use may have affected any previous treatment

9. Tell me about what made you decide to contact FAST/ YAP/ North Dublin Community Care Service for help

Section 2 – Investigating the Persons Understanding of Quality of Life

- 1. Tell me what your experience of being happy is in your daily life**
(Prompts if needed)
Mood and outlook
Scale 1-10
Memories of happiness
- 2. Tell me what being happy means to you?** (Explain on scale?)
- 3. Tell me how you imagine you look like being happy, can you paint a picture?**
- 4. Tell me what your experience of being unhappy is in your daily life**
(Prompts if needed)
Mood and outlook
Scale 1-10
Memories of happiness
- 5. Tell me what being unhappy means to you?** (Explain on scale?)
- 6. Tell me how you imagine you look like being unhappy, can you paint a picture?**
- 7. How satisfied are you with your life at the moment?**
(Prompts if needed)
Compare to ten years ago
- 8. Is there anything that could happen to increase your satisfaction with life?**
- 9. How does your satisfaction with life effect your daily life?**
(Prompts if needed)
 - i. Frustration/ Calm
 - ii. Motivation
 - iii. Anger
 - iv. Sadness/ Happiness
- 10. Tell me about what a normal typical day is like for you**
 - Tell me about some of your daily thoughts/ feelings/ or actions
 - How often do these happen?
- 11. Untypical day – really good**
 - Tell me about some of your daily thoughts/ feelings/ or actions
 - How often do these happen?
 - When your faced with a great day can you tell me how you react to that?
- 12. Untypical day – really bad**
 - Tell me about some of your daily thoughts/ feelings/ or actions
 - How often do these happen?
 - When your faced with a challenge can you tell me how you deal with it
- 13. (Refer back to typical day) - Tell me about your daily life and how you go about doing your daily tasks that need to be done**
 - a. Compare when you get all tasks done vs when you don't get all your tasks done
- 14. How often would you have days when you get stuff done compared to when you don't get things done?**
- 15. Tell me about what you believe is essential for you to have a good QoL**
- 16. What changes would you make now to your life to improve your QoL**
 - Add things?
 - Take things away?

Section 3 – Alcohol and Quality of Life

- 1. Tell me about how you think alcohol has affected your Quality of Life over time**
(Prompts if needed)
 - Physical health
 - Partners, Family, Friends
 - Education/ Work
 - Finance
 - Housing
 - (Mental Health)
- 2. Tell me about how you think alcohol has affected your thoughts/ feelings/ actions**
- 3. Tell me about how you think alcohol has affected your ability to complete everyday tasks**
(Prompts if needed)
 - Shopping
 - Cleaning
 - Self-Care
 - Eating
 - Family Care
- 4. Could you tell me the people that you are in close relationships with?**
(Prompts if needed)
 - Partner, Family, Friends
- 5. Tell me about how you think your alcohol use has affected these close relationships**
(Prompts if needed)
 - General and then go through one by one
- 6. Could you tell me about the relationship between your alcohol use and other substances?**
 - a. Does one influence the other?
- 7. Tell me about how you think this substance/ substances affects your close relationships**
- 8. Tell me about how this substance/ substances affects your QoL**
- 9. Could you tell me about the relationship between your alcohol use and other problem behaviours?**
- 10. Tell me about how you think the problem behaviour affects your close relationships**
- 11. Tell me about how the problem behaviour affects your QoL**
- 12. In what ways would you like to see your QoL improve over the next 6 months?**

D.2 Interview Guides Phase Two

Section 1 –Alcohol Use in the Family and Support

- 1. Tell me about alcohol use by members of your family.**
(Prompts if needed)
 - i. How much do they drink roughly?
 - ii. When/ how often do they drink?
- 2. At what point did you first realise that alcohol was a problem in your family?**
- 3. Tell me about how you think it got to that point? or Why do you think it became such a problem?**
- 4. Tell me about alcohol treatment in your family**
- 5. Tell me about your own experiences of support for these issues around alcohol in your family (including any previous support and current support)**
(Prompts if needed)
 - i. Is this your first-time seeking help for familial alcohol use?
 1. If no, how many previous times have you sought help?
 2. What help? Group Support, Outpatient, Counselling?
 3. Tell me more about your own experience of treatment program X
(Pros/ Cons)
- 6. If any, tell me about any other substances that you feel impacts your homelife**
- 7. If any, tell me about any other addictive behaviours that you feel impacts your homelife**
- 8. Tell me about what made you decide to contact FAST/ YAP/ North Dublin Community Care Service for help (If relevant)**

Section 2 – Investigating the participant’s Understanding of Quality of Life

- 1. Tell me what your experience of being happy is in your daily life**
(Prompts if needed)
 - Mood and outlook
 - Scale 1-10
 - Memories of happiness
- 2. Tell me what being happy means to you? (Explain on scale?)**
- 3. Tell me how you imagine you look like being happy, can you paint a picture?**
- 4. Tell me what your experience of being unhappy is in your daily life**
(Prompts if needed)
 - Mood and outlook
 - Scale 1-10
 - Memories of happiness
- 5. Tell me what being unhappy means to you? (Explain on scale?)**
- 6. Tell me how you imagine you look like being unhappy, can you paint a picture?**
- 7. How satisfied are you with your life at the moment?**
- 8. Is there anything that could happen to increase your satisfaction with life?**
- 9. How does your satisfaction with life effect your daily life?**
(Prompts if needed)
 - i. Frustration/ Calm
 - ii. Motivation

- iii. Anger
- iv. Sadness/ Happiness

10. Tell me about what a normal typical day is like for you

- Tell me about some of your daily thoughts/ feelings/ or actions
- How often do these happen?

11. Describe an untypical day – really good

- Tell me about some of your daily thoughts/ feelings/ or actions
- How often do these happen?
- When you are faced with a great day can you tell me how you react to that?

12. Describe an untypical day – really bad

- Tell me about some of your daily thoughts/ feelings/ or actions
- How often do these happen?
- When you are faced with a challenge can you tell me how you deal with it

13. (Refer back to typical day) - Tell me about your daily life and how you go about doing your daily tasks that need to be done

- a. Compare when you get all tasks done vs when you don't get all your tasks done

14. How often would you have days when you get stuff done compared to when you don't get things done?

More specific here to QoL

15. Tell me about what you believe is essential for you to have a good QoL

16. What changes would you make now to your life to improve your QoL

Add things?

Take things away?

Section 3 – Alcohol and Quality of Life

1. Tell me about how you think alcohol use in your family has affected your Quality of Life over time

(Prompts if needed)

Physical health
Partners, Family, Friends
Education/ Work
Finance
Housing
(Mental Health)

2. Tell me about how you think alcohol use in your family has affected your thoughts/ feelings/ actions

3. Tell me about how you think alcohol use in your family has affected your ability to complete everyday tasks

(Prompts if needed)

Shopping
Cleaning
Self-Care
Eating
Family Care

4. Could you tell me the people with whom you are in close relationships?

(Prompts if needed)

Partner, Family, Friends

5. Tell me about how you think alcohol use in your family has affected these close relationships

(Prompts if needed)

General and then go through one by one

Are you asking about changes to QoL when their family member has been having treatments/
different sorts

6. In what ways would you like to see your QoL improve over the next 6 months?

Appendix E: Debriefing Sheets

E.1 Debriefing Sheet Phase One

Why are we carrying out this study? It is well documented that alcohol use can affect many people. Ireland ranks second highest in the world for rates of binge drinking. It has also been revealed that 3.8% of the Irish adult population is alcohol dependent, with research also reporting that the levels of alcohol dependency are rising. This study is concerned with Quality of life (QoL) and how understanding might help improve treatment for individuals with problem alcohol use.

How was this achieved? Taking part in this study required you to take part in an interview that focused on what QoL means to you, how you experience it from day to day, and your problem alcohol use.

Main research question. This study was designed to investigate what QoL means to individuals with problem alcohol use and how they experience QoL.

Why is this important to study? Understanding what QoL means to those with problem alcohol use and how they experience it from day to day will help to tailor treatment more specifically to the needs of these individuals. This may help to improve treatment and its outcomes.

What if I want to know more? Individual feedback will not be provided in the case of this study. However, a one-page summary of the study can be made available following completion of the study to those who make contact with the research team. If you would like a one-page summary you can contact the researcher at eoghan.scott4@mail.dcu.ie.

If you have any questions about the study or wish to raise an issue that you have with the study, its content or methods, please contact the below. You can contact the researcher directly if you have any questions about the study: Eoghan Scott, eoghan.scott4@mail.dcu.ie.

If you have any problems with the study or encountered any when doing the study, please contact the primary research supervisor: Professor Anne Mathews, anne.mathews@dcu.ie

If participants have any concerns about this project and wish to contact an independent person outside the study, please contact the DCU Ethics committee (REC): rec@dcu.ie

If you have any concerns about your emotional wellbeing after taking part in this study, we advise you to discuss these concerns with your keyworker, care worker or counsellor. Also, please see below a list of numbers that may be of use if you feel distressed in any way.

Pieta House: 01-8840532/ 01-8831000

Alcoholics Anonymous: 01-8420700

The Samaritans: 01-6710071

E.2 Debriefing Sheet Phase Two

Why are we carrying out this study? It is well documented that alcohol use can affect many people. This study is concerned with having a greater understanding of the meaning and experiences of Quality of life (QoL) for adult family members, and how understanding it might help improve interventions for family members of individuals with problem alcohol use.

How was this achieved? Taking part in this study required you to take part in an interview that focused on what QoL means to you, how you experience it from day to day, connected with your family member's problem alcohol use.

Main research question. This study was designed to investigate what QoL means to adult family members of individuals with problem alcohol use and how they experience QoL.

Why is this important to study? Understanding what QoL means to those family members of individuals with problem alcohol use and how they experience it from day to day will help to tailor interventions more specifically to the needs of these individuals.

What if I want to know more? Individual feedback will not be provided from this study. However, a one-page summary of the study can be made available following completion of the study to those who make contact with the research team. If you would like a one-page summary you can contact the researcher at eoghan.scott4@mail.dcu.ie.

If you have any questions about the study or wish to raise an issue that you have with the study, its content or methods, please contact the below. You can contact the researcher directly if you have any questions about the study: Eoghan Scott, eoghan.scott4@mail.dcu.ie.

If you have any problems with the study or encountered any when doing the study, please contact the primary research supervisor: Professor Anne Mathews, anne.mathews@dcu.ie

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