# Coping with Carbon Monoxide (CO) exposure: An Interpretative Phenomenological Analysis

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# Abstract

**Background:** Through this research, I explore the lived experiences of 11 participants who are coping with unintentional exposure to carbon monoxide (CO), using Interpretative Phenomenological Analysis (IPA). Approximately 60 people of all ages lose their lives from preventable CO exposure in England and Wales each year (NHS, 2019), and people who survive CO exposure may be injured and have long-lasting, burdensome sequelae (Chavouzis and Pneumatikos, 2014). People also have to cope with the traumatic experience of the exposure itself.

CO is produced during the incomplete combustion of carbon-based material (Mandal et al., 2011; Kokkarinen et al., 2014), and is known as the 'silent killer' (Long and Flaherty, 2017), as it is undetectable to human senses and small amounts are extremely harmful. Academic and medical literature on CO is written from the perspective of healthcare professionals, and has therefore failed to address the perspectives of people who are coping with this experience. This research seeks to rectify this situation.

**Methodology and findings:** An unstructured interview approach, where people were visited twice, was used to generate data. Two dyads were included in this number. This data was then analysed using IPA, where four superordinate themes emerged: 'traumatic experience', 'power, justice and judgement', 'identity and connectedness' and 'everybody seems to be in the dark'.

**Discussion and conclusion:** A feature of the research was the lack of voice afforded to those who have been exposed to CO. This often led to feelings of isolation. The participants also continue to face many challenges due to their exposure. As well as substantial sequelae from the exposure itself, they also face issues due to the lack of knowledge about CO. My analysis suggests that many participants coped well with the effects of CO exposure. However, there were complexities around perceptions about the self and identity. Concepts of power and justice also operate with regards to living with the aftermath of exposure to CO.

# Acknowledgements

This research has by no means been a solo effort, and I am profoundly grateful to all of those mentioned here:

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I dedicate my research to all of those affected by CO exposure.

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# Chapter one: Introduction

# Introduction to thesis

CO causes preventable deaths and injuries (APPCOG, 2015; Ghosh et al. 2016); those who are exposed can suffer long-lasting, sometimes permanent consequences (Hopkins et al., 2006). My research focuses on the lived experience of those who have been unintentionally exposed to CO, as this group have not consistently been allowed a voice – that is, they have attempted to voice their concerns, but these may have been overlooked or misunderstood. This introductory chapter presents the rationale for the research, the research questions themselves, and discusses the use of IPA in the context of CO exposure. It also presents both an introduction to my position as a researcher and my motivations for conducting this research, and adds some background information about CO, needed here to assist the reader in the understanding of this complex picture. The chapter also serves to signpost readers through the thesis by giving a concise summary of individual chapters. There is also a brief introduction to the participants themselves, although it is recommended that readers refer to the pen portraits (appendices 1-11) for a necessary and more detailed consideration of their circumstances.

It is recognised, through medical and academic literature, that CO has many undesirable and persistent effects on physiology. However, although this literature shows a general increasing awareness of the dangers of CO exposure, it does not address the concerns of the people who endure exposure to CO, and none of it is written from their own perspective. While there are 'survivor accounts' in the media and particularly on the web pages of the charitable organisations that work with people in this situation, there is nothing throughout the medical or academic literature that takes the perspective of the person or persons who have been exposed to CO. With recognition that studying such perspectives can be used to improve services and interventions for the users of healthcare (NHS, 2015), this innovative research, in exploring this dimension of CO exposure, will therefore seek to address this gap.

IPA is not often *"theory driven"* (Smith et al., 2009 p.42) and expects that only the lived experience of participants with regards to a particular aspect of their lives will be explored within analysis, where theory may then be used to further illuminate the interpretations. In this research, CO exposure, which has not been studied before from this perspective (ibid) afforded the experience for exploration.

I began this research by speculating how it might feel to experience exposure and CO-related injuries. Questions arose such as: how do people cope with CO exposure and take up their lives again, while perhaps unable to function at the same capacity anymore? What does it mean to be a person coping with the aftermath of CO exposure? This line of questioning led to the formulation of the research questions that are explored in this thesis:

- What is the experience of people who are exposed to CO?
- How does the exposure affect their lives?
- How do they experience the aftermath of that exposure?

Questions of this type lend themselves to in-depth interviews of the sort gathered in lived experience studies. Interpretative Phenomenological Analysis (IPA), as it seeks to examine how people make sense of their major life experiences, is the optimum methodology to allow these participants to be heard where they currently are not heard. IPA developed as a response to such concerns in psychological research (Smith, 1996), and holds that: *"human beings are sense-making creatures"* (Smith et al., 2009 p.3), so the participants and I form the meaning together, as detailed in the discussion chapter, rather than the research merely recording or echoing what the participant has said.

As a qualitative methodology, IPA does not use hypothetico-deductive reasoning and makes no claims for generalisation. Rather, it is phenomenological, interpretative and has an idiographic commitment to exploring the individual perspective in depth (Smith, 2011a). The primary focus of

IPA research should be the participants (Smith et al., 2009), as it is their experience that is paramount.

Smith and Eatough (2007) suggest that IPA can be considered from a theoretical perspective, that is, analysis and findings can be related to the researcher's personal and professional experience. As an academic with a background in nursing, I quickly became immersed in this subject. I could appreciate the hitherto unknown, to me, health effects and sequelae of exposure, and felt motivated to work with people who had been unintentionally exposed to CO. I saw the subject as an issue affecting those who have been exposed in all areas of their lives: apart from physical symptoms that may resolve or persist, participants may be affected in other ways. This includes diverse cognitive and affective problems, as well as the more 'social' effects of issues around home- or work-life and, indeed, the wider perspectives of any treatment or support that participants attempted to access. I did not adopt the role of the *"positivistic model of the absent or neutral researcher"* (Mauthner and Doucet 2003, p.415); as I realised how important the research was felt to be by the participants themselves, I could not remain dispassionate and I have become an advocate for the participants by sharing the research findings as much as possible. Ladegaard (2015) saw his roles as researcher and volunteer at a refuge as *"complementary rather than contradictory"* (p.192); I felt that in advocating for them and providing them with a means to share their experiences through analysis of their accounts, I was very much in the same position. While I found that isolation due to a lack of appropriate knowledge about CO from those around them is a common feature of the experience of exposure for participants, I also found that they understood and had learned a great deal about it themselves, but often found difficulty in being heard. In an attempt to redress this balance, I have included their voices throughout each iteratively-constructed chapter, in order to allow them to be present throughout the thesis.

Here, I include a warning to readers. The accounts tell of the effects of CO exposure, and are very frank. At times they are harrowing in their nature. The interviews allowed a safe space for the participants to tell me in detail what had occurred, and in accordance with IPA I have presented what was told as openly as it was told to me. This is a vital part of the research, and I hope that in sharing, candidly, what the participants endured, that their suffering is acknowledged and their voices are heard.

## CO: Stating the problem

CO is produced by incomplete combustion of carbonate fuels, such as gas, coal, wood, charcoal, petrol and as happens in portable generators (Buchelli Ramirez et al. 2014; de Juniac et al., 2012). In modern domestic settings, energy efficient housing results in more airtightness and fewer draughts (Bolton, 2016), therefore meaning gas appliances that are poorly fitted and/or repaired and maintained can be a source of CO, as can blockages of vents, flues and chimneys (Kokkarinen et al., 2014). Statistics on mechanisms of unintentional exposure are difficult to obtain and the number of incidences may well be underestimated (Mandal et al., 2011). De Juniac et al.'s (2012) work cited data from the Carbon Monoxide and Gas Safety Society (COGSS) (2009) (UK) which showed that fatalities (unintentional and non-fire-related) occurred from problems with heaters, boilers and cookers, with mains gas accounting for 38.3% of the deaths associated with CO during the period between 1996 and 2007, although the authors cite some issues with this data. Homes with gas ovens which are properly maintained have CO levels that vary between 5-15 parts per million (ppm), compared with 0.5-5ppm where there is no gas oven. Homes with improperly maintained gas ovens may have levels of 30ppm or higher (Environmental Protection Agency (EPA) 2017). Unintentional exposure occurs, unsurprisingly, more frequently in the winter months (Mandal et al., 2011; de Juniac et al., 2012; Ho et al., 2012; Ormandy and Ezratty, 2012).

## Harm from CO

Despite being a preventable cause of death and injury, 53 people were recorded as dying from unintentional CO exposure in England and Wales in 2015 (ONS, 2016), with the number of deaths currently stated to be slightly higher at approximately 60 per year from the NHS (NHS, 2019). In the region of 4,000 people are thought to attend A&E departments annually as a result of CO exposure (APPCOG, 2015; APPGSG, 2011), resulting in around 400 hospital admissions (Mandal et al., 2011). It is, however, acknowledged that these figures are an underestimation (Bolton, 2016; Ghosh et al., 2016) and that accurate morbidity and mortality rates are no doubt higher (Wolf et al., 2017). Of course, no statistic can account for those individuals exposed to lower levels of CO and then, although unwell as a result, have either been misdiagnosed or never presented themselves to a healthcare professional. Research from the Gas Safe Register (2016) reports a high level of dangerous gas appliances (one in five homes has at least one unsafe gas appliance), concomitant with a high level of ignorance about the safety checks that are a legal requirement for landlords to undertake annually (and are recommended for homeowners) (HSE, 2018). Many occupants may also not be knowledgeable about the risks associated with CO (Mandal et al., 2011). The true number of individuals, families and communities who suffer due to CO may therefore be far higher than the current research may estimate.

## How much is too much?

Discussions about CO often start with a focus on how much CO in a particular atmosphere constitutes danger. While it is considered extremely hazardous to endure exposure to an atmosphere that contains more than 100 parts per million (ppm) for any period of time (Chavouzis and Pneumatikos, 2014), the World Health Organisation (Raub, 1999; WHO, 2010) recommends that people should not be exposed to more than 87ppm for 15 minutes as a safe limit. Public Health England (PHE) recommend the same guidelines, with occupational standards of 30ppm for an eight-hour reference period and 200ppm for a 15-minute reference period (PHE, 2016; WHO, 2010; HSE 2011), as illustrated in table 1:

## Table 1: Guidelines for CO limits

<table>
<tr><td colspan="3"><b>Indoor air quality guideline CO</b></td><td colspan="2">100mg/$m^3$ (87ppm) for 15 minutes<br>35mg/$m^3$ (30ppm) for one hour<br>10mg/$m^3$ (8.7ppm) for eight hours<br>7mg/$m^3$ (6.1ppm) for 24 hours</td></tr>
<tr><td rowspan="2"></td><td colspan="2">LTEL (8 hour reference period)</td><td colspan="2">STEL (15 minute reference period)</td></tr>
<tr><td>ppm</td><td>mg/$m^3$</td><td>ppm</td><td>mg/$m^3$</td></tr>
<tr><td><b>WEL</b></td><td>30</td><td>35</td><td>200</td><td>232</td></tr>
<tr><td colspan="5">WEL – workplace exposure limit, LTEL – long term exposure limit, STEL – short-term exposure limit</td></tr>
</table>

*Note: 1ppm = 1.165mg/$m^3$ or 1mg/$m^3$ = 0.858ppm at 20°C and 760mmHg (WHO, 2010)*

An updated edition of the Health and Safety Executive (HSE)'s workplace exposure limits came into place in 2018, reducing the WEL as detailed above to 20ppm for the LTEL and 100ppm for the STEL. These new limits will come into force by 2023 (HSE, 2019).

The United States' Environmental Protection Agency (EPA) has slightly different standards, with 9ppm as an eight-hour average and 35ppm as a one-hour average. These standards have not been changed since 1971, when they were established to provide the necessary protection for the public while including an *"adequate margin of safety"* (EPA, 2011 p. 54294). While death and injury from CO exposure has fallen since the time when these standards were established (ibid), people continue to lose their lives, their loved ones and their health from CO exposure. Survivors may have to contend with distressing symptoms, with or without a formal diagnosis (Walker and Hay, 1999), and potentially without support from healthcare professionals (APPCOG, 2017). It is also difficult to comment with certainty about safety in any level of CO.

## Terminology: Exposure versus poisoning

For the purposes of clarity all participants in this study are referred to as having suffered 'exposure' rather than 'poisoning'. One reason for this is the lack of consistency in the somewhat arbitrary positioning of thresholds for definitions of poisoning in the context of CO (Bolton, 2016; Brucelli Ramirez et al., 2014). Some participants could be placed in 'acute' (higher concentrations of CO exposure, usually over a shorter time) or ‘chronic’ (lower concentrations of CO exposure, usually over a longer time) ‘poisoning’ categories according to Wright’s (2002) definitions, but not all participants can be classified so comfortably, and most do not have evidence in the form of the biomarker carboxyhaemoglobin in their blood results that would provide them with physiological evidence of such a status. This is due to carboxyhaemoglobin quickly starting to degenerate once an exposed individual is in fresh air (Weaver et al., 2000; Weaver et al., 2014). Where there was emergency medical intervention for participants (Vivienne, Bookie, Tisha and Ajay), oxygen therapy of some form was used, which hastened this degeneration process (Nikitopoulou and Papalimperi, 2015). Bleecker (2015) estimates an accurate carboxyhaemoglobin reading would be determined by a reading taken just two minutes after CO exposure was recognised and the individual removed from its source. There also is a lack of physical evidence from environments, that is, readings of CO from that environment recorded by an engineer called to the scene. Where engineers were present, ‘true’ readings were generally not possible to obtain, as when CO exposure is suspected people are advised to turn off all appliances and ventilate their properties as much as possible, and evacuate the premises, thus allowing the gas to disperse (HSE, 2019a).

Participant accounts are divergent, as some were in positions where CO exposure was an emergency situation and it was recognised that they required immediate hospital treatment. Others found great difficulty in convincing their General Practitioner (GP) that they were indeed ill, presenting often with non-specific symptoms which defied explanation. Many did not tell me, and some could not tell me, about the actual concentrations of CO that were found at the scene or as a result of blood tests, and it is for clarity, therefore, that I have used the term ‘exposure’ throughout. All of the participants’ experiences converge, to varying degrees, in the lack of knowledge about CO that was encountered, frequently from healthcare professionals. However, the participants themselves became knowledgeable about CO since their exposure, often as a form of problem-based coping (Folkman and Moskowitz 2004). This meant that they largely identified themselves as having acute (higher concentrations of CO over a shorter time) or chronic (lower concentrations of CO over a longer time) CO exposure/poisoning (Wright, 2002).

## Thesis structure

The literature review chapter (chapter two) contains further information regarding what is currently understood about CO and information on coping and traumatic experience. As such it forms a critical, evaluative background information section, to give the reader context as to what information is already known about what the participants endured and continue to endure, and presents this experience as a traumatic event.

Methodological issues are presented over three chapters. Chapter three discusses the philosophical basis that underpins qualitative research in general and IPA in particular, and includes reflexivity as an important element of this research process. Chapter four is concerned with the data collection methods used for this research. These include issues around the decisions taken in interviewing the participants twice and using the BNIM approach, the use of dyads, sampling and ethical considerations. Chapter five details the analysis of the data.

Chapters six and seven present the findings. In order to present the findings to readers in a coherent way, the participants were separated into two groups, according to participants' self-identification as exposure to higher or lower concentrations of CO. One group (group one) therefore suffered shorter-lived, isolated incidents of exposure that caused severe symptoms, such as was the case for Vivienne and Bookie, and the other group (group two) is comprised of those participants who had either persistent or recurrent exposure to CO, again at unknown, but possibly lower levels, such as Sarah and Kate. In addition to making the data easier to access for readers, this was also a data-driven decision, as participants generally themselves had learned so much about CO that they categorised themselves as having experienced 'acute' or 'chronic' exposure or 'poisoning'. Matt, for instance, has never been formally diagnosed as having CO exposure of any kind, but at interview revealed that he clearly appreciated that he had been exposed to a higher concentration of CO over a short period. Showgirl was exposed to CO due to her neighbour's use of his open fire with its ineffective chimney, and felt ill when she could smell the smoke from his fire inside her house, where the smoke was seeping through. This happened fairly often over a period of several months, indicating recurrence, but she was exposed to higher levels of CO at times (see appendix 11). The scenario described above, where she called the Emergency Gas Helpline (National Grid, 2019) and vacated and ventilated the property, meant a lack of proof of the presence of CO at all. She again identified herself as having 'chronic CO poisoning', however.

Three superordinate themes for group one and four for group two became apparent:

## Table 2: Superordinate themes and groups:

| | **Superordinate theme 1** | **Superordinate theme 2** | **Superordinate theme 3** | **Superordinate theme 4** |
|---|---|---|---|---|
| **Group one (higher concentrations/shorter time)** | Traumatic experience | Power, justice and judgement | Identity and connectedness | |
| **Group two (lower concentrations/longer time)** | Traumatic experience | Power, justice and judgement | Identity and connectedness | Everybody seems to be in the dark |

The discussion chapter (chapter eight) communicates the findings in relation to the literature discussed in this introduction and in chapter two. It also presents new literature in light of the nature of the findings. Chapter nine summarises the study and includes ideas for future work, as well as presenting the limitations of the current study.

# Introducing the participants

As stated, the participants remain at the centre of the thesis throughout, in keeping with IPA's idiographic commitment (Smith et al., 2009) and are thus introduced briefly here. In order to give the reader a detailed description of the events that led to their CO exposure and the aftermath of that exposure, I have included ‘pen portraits’ for each participant (appendices 1-11). These portraits capture the sense of who the participants are, and provide the reader with more information about the context of their diverse experiences of exposure to CO. Issues such as participants’ varied symptoms, sequelae and types of encounter with healthcare professionals are listed in tables 3 and 4 (appendices 12-13) are also incorporated here, again, in order for the reader to come to know the participants. I would advise readers to familiarise themselves with these synopses in order to gain a more complete and comprehensive picture of what each person endured due to CO exposure. I have also included the symptoms that they recorded as occurring in any family members (or a neighbour, in Sarah’s case). These are included as part of the individual participant’s experience, and although at first glance it may seem as though these inclusions are not in keeping with the idiographic nature of IPA (Shinebourne 2011), the participants chose to discuss their experiences by communicating what happened to others. For families, couples, and people who share accommodation, CO exposure is a collective experience and this therefore forms part of the research, as it is part of their experience.

There are 11 participants from locations in the north and south of Britain. They constitute a range of adult ages at the time of exposure, and all happen to be from professional working backgrounds. The following short section introduces them in a brief snapshot; a convenient and immediate summary of what may be found in the pen portraits. The participants are presented here in the order in which I met them; this order continues in all tables and appendices throughout the thesis. All names are pseudonyms.

## Curstaidh: Group two (appendix one, p. 273)

Curstaidh rented a house where she lived with her then teenaged son. While there were several problems with the house, over the course of the winter that they lived there they were both exposed to lower levels of CO through the use of the open fire and inadequate chimney. Curstaidh had respiratory problems and her son was treated for migraines until the CO was discovered. She found that no-one was equipped to support them in addressing the issues that she then had with the landlord.

## Bookie: Group one (appendix two, p. 275)

Bookie lived with his mother. They had cavity wall insulation fitted, but this disrupted the connection between the boiler (located in the garage adjoining the house) and the interior of the house itself. The fitters should have called a gas engineer, instead of incorrectly advising Bookie. Sadly, this resulted in the death of Bookie’s mother from high levels of CO from the damaged boiler connection. Bookie was hospitalised for a night; he was interviewed by the police regarding the death of his mother. There followed a protracted court case due to the Health and Safety Executive’s (HSE) already ongoing investigations of this company, which ultimately resulted in the company being found negligent.

## Kate: Group two (appendix three, p. 277)

Kate lived in a newly-built house with her then husband and son. She ran her own, very successful, business from home. Despite ill health, including lengthy hospitalisation for collapse and chest pain, it was a maintenance check on the boiler that revealed incorrect installation, thereby subjecting the family to constant lower levels of CO for three years. Kate in particular has long term sequelae from this time, including significant cognitive issues necessitating closing her business and changing her career. She worries that her health is continuing to decline.

## Be the change you want to see in the world (known as ‘Be’): Group two (appendix four, p. 279)

Be, her husband and three children moved to a house where they were exposed to lower levels of CO through a faulty boiler over around six years. All of the family had different symptoms; Be was *“desperately”* (line 357) trying to seek medical help but to no avail. She received various diagnoses during this time; she also found it very difficult to gain medical support after the CO exposure came to light, as the HCPs she consulted did not know about lower level CO exposure or its after effects.

## Vivienne: Group one (appendix five, p. 282)

Vivienne and his partner were on holiday when they were exposed to a high level of CO from a barbeque that had gone cold but was still producing CO. His partner sadly died; Vivienne suffered the effects of the CO in addition to a serious injury where he had lain unconscious for many hours, resulting in a crush injury to his arm. Vivienne was arrested for his partner's murder before it was realised that CO was the cause of her death. Like some other participants, he now campaigns to raise awareness of CO.

## Lizzie: Group two (appendix six, p. 284)

The cause of Lizzie's CO exposure was a gas fire. The fire was not faulty, but building work had been done on the roof of the family's home before they lived there and the resulting debris had been left down the chimney, blocking the escape route for the exhaust fumes from the fire. All of the family were affected to some degree, but Lizzie already had a pre-existing condition which made investigations into her symptoms more complex. She also experienced resistance from her GPs as they assumed that her symptoms were part of the already diagnosed condition. Under the contract from the gas provider, the gas fire had been assessed as safe during the previous annual check.

## Sarah: Group two (appendix seven, p. 286)

Sarah had annual gas safety checks performed during her three-year residency in a rented top-floor flat; however, none of those engineers performing the check had gone into the loft to check that the fumes were properly exiting the property. When this check finally happened, it was discovered that Sarah would have been exposed to lower levels of CO every time the boiler was on because there was no connecting pipe taking exhaust gases from the boiler to the outside. Sarah also had a pre-existing condition and again, there was difficulty in recognising the issues around lower level exposure to CO.

## Ajay and Tisha: Group one (appendix eight, p. 288)

This newly married couple were interviewed, at their request, as a dyad. They were exposed to CO which rose up into their home with the heat of the faulty gas fire from the flat below. This occurred over a weekend, during which the occupant of the downstairs flat died, leaving the dangerous appliance switched on. Tisha was admitted to their local A&E on the Sunday morning, after collapsing, but no-one thought to investigate an environmental source for this collapse, which was presumed to be a fainting spell (syncope) and she was discharged. They were both dangerously ill by the Monday morning, and received hyperbaric oxygen therapy.

## Matt (and Daisy): Group one (appendix nine, p. 290)

Matt was exposed to CO through his work; conforming to the usual practice of the time, he used a generator inside an empty building where he needed an electrical supply. He collapsed but managed to phone for help. A&E staff thought that he just had a syncopal (fainting) episode. He quickly noticed difficulties with memory and cognition, and with expressing emotions. This latter issue especially has continued to be a problem for him. We agreed that his wife, Daisy, would be able to give her valuable perspective on how things changed for him. Her comments have not been analysed here but do provide much a much appreciated context for Matt's experience.

## Showgirl: Group two (appendix 10, p. 292)

Showgirl's adjoining neighbour is a builder. She suspects that the rubbish that she sees him bring home is burnt in his fireplace, as she can smell smoke inside her house when his fire is lit (another builder suggested that this is due to the liner in his chimney being faulty). This coincides with her being unwell. She has tried to address the situation through Environmental Health, but found that they, too, did not know about lower levels of CO exposure.

This very brief introduction to the participants places them at the centre of the thesis. The next chapter reviews the literature further exploring the physiological effects of CO, and place it within the context of coping with a traumatic experience.

# Chapter two:

# Carbon monoxide exposure and coping with trauma

# Introduction

In this section I further explore the literature on CO and the effect that this hazardous gas has on bodily systems, whether that harm be from exposure to higher concentrations of CO which happens over a shorter period or exposure to lower concentrations of CO over a longer time period. The terms ‘acute’ and ‘chronic’ ‘poisoning’ are often used by the authors of papers in that extant literature. These terms will therefore be cited in the examination of that literature for the remainder of this analytical section of this chapter, which will also introduce some of the issues around measuring carboxyhaemoglobin as a biomarker for CO exposure, and hyperbaric oxygen therapy as a postulated treatment for CO exposure. Participants of the study are given a voice in this chapter, however, the nature of this scientific discussion and explanation of the biophysiological effects of CO means that much of this section is rather technical in its tone and far less inductive when compared to other chapters. This is necessary and provides readers with context of the variable situations around CO exposure. This information is presented alongside information about coping with trauma, giving context to exposure to CO as an occurrence which is traumatic and for which coping strategies need to be found.

The medical and academic literature regarding human harm from CO is, as stated, largely written from the perspective of healthcare professionals treating those who have been exposed. In particular, this literature is predominantly concerned with single case study examples concerning individuals or families following exposure to a high concentration to CO over a comparatively short period, and as such there are some issues when considering that literature. For instance, as discussed in the next section, there are few systematic reviews and no Randomised Controlled Trials (RCTs) available. It also contrasts with the perspective that I have taken in this research, where the person who has suffered the exposure is the focus of the research, regardless of how that exposure came about.

## The literature around CO

The literature regarding CO was searched through various databases, including the Cochrane Library Database of Systematic Reviews, and EBSCO host searches using the ‘relevance ranking’ filter of the following databases:

- Academic Search Complete
- MEDLINE
- Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with full text
- SPORTDiscus with full text

Search terms were explored singly and in combination, and included, for this section, Carbon Monoxide, CO, exposure, poisoning, acute, chronic, sequelae and Hyperbaric and Hyperbaric Oxygen Therapy (HBOT). Additions such as ‘lived experience’ to these terms confirmed that there was an absence of any such studies. As mentioned, there are no RCTs available around CO research, and few peer-reviewed systematic reviews, with the exception of Nikitopoulou and Papalimperi’s (2015) systematic review and the Cochrane Library Reviews of, firstly, Jurrlink et al. (2005), and the updated Buckley et al. (2011), all of which are concerned with HBOT and therefore treatment of CO exposure, rather than the experience of CO exposure itself. In addition to these papers, Liao et al.’s recent (2019) retrospective study of Taiwanese Intensive Care Unit (ICU) treatment of patients with CO exposure from 2001 to 2010, Ghosh et al.’s (2016) retrospective study of hospital admissions due to CO exposure in England over the same time period, and Tirosh and Schnell’s (2016) systematic review regarding heart rate variability in those who have been exposed to CO, stand out in the literature about CO exposure as being particularly rigorous. Nikitopoulou and Papalimperi’s (2015) paper has been subjected to the Critical Appraisal Skills Programme (CASP) (2018) for evaluation as an example of the usefulness of this approach to informing the research (see appendix 14).

The majority of the rest of the literature has had to be more informally appraised, as it does not attempt to communicate or evaluate assertions or claims regarding treatment of CO exposure, but, as stated, consists of shorter reports on the symptoms and progression of patients who were exposed to CO, written by healthcare professionals who treated them. This means that criteria such as CASP appraisal tools are not suitable as the criteria itself would have had to be interpreted rather too flexibly; instead, papers were read and included here due to their relevance ranking and inclusion on the above databases. Literature reviews were found to be useful; those by Roderique et al. (2015), Hopkins et al. (2006) and Mandal et al. (2011) have therefore also informed this chapter. Roderique et al.'s (2015) literature review is a comprehensive examination of the current theories around mechanisms of harm, therapies, and advancements in treatment; Hopkins et al. (2006) offer a partial literature review around damage to the basal ganglia as a consequence of CO exposure as a part of their prospective cohort study, and Mandal et al. (2011) offer a further literature review as a part of their public health guidance development for frontline staff education regarding CO exposure. The retrospective study of Pepe et al. (2011), which is concerned with delayed sequelae of CO exposure, was also employed to present the research on this topic.

Some grey literature has also been included. This mainly takes the form of the policy documents provided by bodies such as Public Health England (PHE). APPCOG reports (2105; 2017) are also defined as grey literature, as they are publications with little general distribution (Auger, 1998). Nevertheless, this literature proved to be very useful to this research.

## CO and carboxyhaemoglobin

It is understood that a diagnosis of CO exposure is primarily based on a recent history compatible with CO exposure, symptoms consistent with CO exposure, and laboratory findings of elevated carboxyhaemoglobin (Chavouzis and Pneumatikos, 2014). However, there are potential issues with identifying exposure in this way, and diagnosis of CO exposure can be challenging: Bennetto et al. (2008), for example, present the case study of a seriously ill man whose symptoms were treated for three weeks before his history of CO exposure became known. Sykes and Walker (2016) describe the *"not uncommon"* (p. 441) circumstance for healthcare professionals of a near-fatal incident of exposure being brought to the awareness of the emergency services; the history of such a patient may reveal many preceding months of undiagnosed ill-health. This reflects the more typical and readily available academic and medical literature on CO.

Carboxyhaemoglobin levels, however measured (Chambers et al., 2008), do not correlate well with symptoms of exposure or with clinical outcomes for those exposed in terms of both presenting and lasting symptoms (Hampson and Hauff, 2008; Raub et al., 2000; Weaver, 2009; Hess, 2017) or delayed onset symptoms (Chavouzis and Pneumatikos, 2014; Pepe et al. 2011) where no carboxyhaemoglobin would be found. Higgins (2005) demonstrates this in reporting a case study where out of five people – two adults and three children – travelling in a poorly maintained car, one child (carboxyhaemoglobin level 35%) was unconscious, but the other two children were reported to be asymptomatic, although they had carboxyhaemoglobin levels of 33.6% and 34.7%.

Roderique et al. (2015 p.47) postulate that the relationship between carboxyhaemoglobin levels and symptom presentation should be *"nearly linear"* if the mechanism of exposure is a reduction in available oxygen leading to hypoxia and therefore assert that hypoxia is *"not enough"* (ibid) to cause all of the symptoms and sequelae that are produced. However, this relationship is far from consistent (ibid; Liao et al. 2019). The theory also fails to explain the cognitive dysfunction symptoms that can develop as long as 240 days after injury, when CO may well have long dissipated and symptoms disappeared (Huijun et al., 2011; Chavouzis and Pneumatikos, 2014).

Laboratory results may also take precedence, when contemplating diagnosis and possible treatment, over the history-taking of an individual's symptoms (Sykes and Walker, 2016). This could potentially lead to misinterpretation and misdiagnosis arising from the suspicion that any presenting symptoms could be caused by something other than CO, which in this circumstance may not be deemed sufficiently elevated to cause those symptoms.

## CO and vulnerability

Authors agree that some people are more vulnerable to the effects of CO exposure. Infants, pregnant women, older adults and those who suffer from existing respiratory and cardiac conditions are more likely to suffer more serious complications at lower exposure doses of CO, due to increased circulatory and respiratory effort and comparatively high metabolic rates (Pepe et al., 2011; HPA, 2011; Townsend and Maynard, 2002; Harper and Croft-Baker, 2004; Su et al., 2014). Foetuses are also included in that group. Foetal haemoglobin is subtly different and has a higher affinity for oxygen than it does after birth (Struchfield et al., 2014). Those with coronary heart disease or chronic obstructive pulmonary disease are also more susceptible to the effects of CO (Chavouzis and Pneumatikos, 2014). This information is long-established; Stewart (1975) argued that any amount of CO exposure would adversely affect an already diseased cardiovascular system. Older adults are also more prone to already having another condition which would account for such symptoms (again meaning that CO exposure may not be suspected). They may also have less physiological reserve, meaning an exposure event may cause more problems (Harper and Croft-Baker, 2004). In addition, older adults are perhaps more liable to stay indoors during colder weather, meaning they may spend a considerable amount of their time in a poorly ventilated room in their home.

Information from the British Heart Foundation (BHF, 2016) shows that an excess of seven million people in the UK live with cardiovascular disease (CVD). Of that number, 2.3 million have coronary heart disease. The WHO’s figures for safe levels of exposure for those affected by CVD are at 30ppm; an increase beyond that number exacerbates symptoms in angina sufferers (WHO, 2010). CO is an acknowledged gaseous air pollutant (WHO, 2008); while it is difficult to single out the differential effects ascribed to ambient CO in the large variance of existing air pollutants, the rate of fatal and non-fatal cardiovascular events is directly related to air pollution (Tirosh and Schnell, 2016; Shah et al., 2013). It is also known that those with respiratory conditions are more likely to suffer exacerbation of their conditions and worse consequences if they are exposed to CO than those without. Again, these conditions are common, with one in five people in the UK living with asthma, Chronic Obstructive Pulmonary Disease (COPD) or another lung condition (British Lung Foundation, 2016). Much work remains to be done to establish the extent of the extra burden that inhaled CO could cause these individuals, and how much could be done to minimise the effects of CO on their existing conditions.

## Acute and chronic exposure

As previously mentioned, the literature on CO and its effects tends to explore shorter-lived episodes of higher concentrations of CO exposure and the consequences of that exposure on the various organ systems of the surviving individual or persons concerned, written from the perspective of the physician-authors (for example, Abdulaziz et al., 2012; Greingor et al., 2001; Liang et al., 2011).

Far fewer examples discussing exposure to lower concentrations of CO exist, meaning that those exposed to CO in these incidents may remain undiagnosed and misunderstood. As discussed and as rightly pointed out by Bolton (2016) and Mandal et al. (2011), this is due at least in part to the difference between the definitions of the terms exposure (where there is the potential for contact with a toxic substance, but without necessarily incurring immediately noticeable adverse health effects) and poisoning (where there are adverse health effects resulting from contact with a particular substance; in this case, the inhalation of CO). The way these terms are used in the literature, meaning that exposure to lower concentrations of CO may be excluded and any resulting symptoms and sequelae regarded as unrelated to CO, has a significant impact on the understanding of the subject area and thus relates directly to the current study. While some participants such as Kate (group two) have life-altering sequelae about which healthcare professionals profess ambivalence as to the cause: *“we think it is, but we’re not, you know, we’re not sure [that the cause of sequelae is CO exposure]”* (Kate, line 274), other participants, namely Matt (group one) and Showgirl (group two), have to date never had CO exposure formally diagnosed by healthcare professionals.

As stated, the current literature generally discusses exposure to CO at higher and lower concentrations as being ‘acute’ or ‘chronic’. Wright (2002), for example, defines poisoning or exposure as being acute, chronic or occult. The first category presents with debilitating symptoms, often following a single exposure to a large amount of CO which involves one or more people who have been affected by the same, identifiable source. This has also been described as exposure for up to 24hrs, while chronic exposure is the result of exposure for longer than 24hrs and includes intermittent exposure (Sykes and Walker, 2016).

Chronic exposure represents a large percentage of exposures and can have a significant impact on individuals (Bolton, 2016; Schildkrout, 2014). While far less space is given to its discussion in the literature, there are some examples, such as Chen et al. (2015), Chen et al. (2013) and Thomsen et al. (2016). Again, these papers are written from the perspective of the physician and not the patient experiencing the situation. This category may be indicated after exposure to CO on more than one occasion, usually at far lower concentrations, when those affected find themselves to be unwell. Repeated, long-term exposure and the resulting symptoms may prompt those affected to seek help from healthcare professionals, but diagnosis of vague, non-specific symptoms is difficult and it has long been postulated that many cases of CO exposure may be unrecognised and/or misdiagnosed (Walker and Hay, 1999; Mandal et al., 2011). This is precisely due to the nature of those symptoms, which tend to mirror common conditions such as influenza or food poisoning (Tam et al., 2012), therefore making a correct diagnosis difficult (de Juniac et al., 2012). As the colder seasons result in the increased likelihood of exposure to CO and a proliferation of viral-type illnesses, this too can contribute to misdiagnoses (Ernst and Zibrak, 1998; Mandal et al. 2011). Some symptoms may be relatively minor and recede when exposure ends, but others may persist and are difficult to live with (Thomsen et al., 2016).

Occult (hidden) exposure happens when exposure to CO is never recognised as such (Wright, 2002). It is often concurrent with chronic exposure, where affected individuals may not seek help as they assign their non-specific symptoms to other causes. Treatment and support are never, therefore, sought by an individual, even though that person might experience burdensome symptoms. As help is never sought, occult exposure may never come to the attention of healthcare professionals. Acute or chronic exposure may also be classed as occult if misdiagnosis occurs, although the help of healthcare professionals has been sought (Wright, 2002). It can be seen that, in concurrence with Mandal et al. (2011), the harms caused by CO remain difficult to quantify. Wright (ibid) goes on to describe CO exposure as a pyramid of presentation condition, where the apex is acute exposure and the base is occult, lower level exposure. The extent of the base of this pyramid remains unknown.

## Signs and symptoms of exposure to CO

Acute CO poisoning is known to be non-specific and highly variable in its presentation (Wolf et al., 2017; Roderique et al. 2015). The Central Nervous System (CNS) is most sensitive to CO exposure, leading to headache, dizziness or dysfunction (such as memory and attention issues, lethargy and fatigue) and progressing to syncope (fainting), seizures and coma (Whitson, 2011), hypotension, severe acidaemia and respiratory collapse (Wolf et al., 2017). Further potential symptoms include vomiting and diarrhoea, confusion, angina and breathlessness (Wright, 2002); mood disturbance, personality changes and dementia (Yeh et al., 2014); disorientation, unsteady gait, exaggerated reflexes and incontinence, along with irritability (Ho et al., 212), muscle pain (Rahmani et al., 2013); vascular damage (Kjeldsen et al., 1972), thrombus formation (Grace and Platt, 1981; de Matteis et al., 2015); dyspnoea (difficulty breathing), chest pain, ventricular arrhythmias and pulmonary oedema (Ho et al., 2012; Tirosh and Schnell, 2016), and acute kidney injury (Kim et al., 2018) as well as vertigo and hearing loss (Seale et al., 2018).

Chronic CO poisoning leads to similar, non-specific issues; flu-like feelings without the development of fever are common, as are symptoms that are similar to food poisoning. Symptoms usually progress as the source of the exposure remains hard to identify and other conditions are investigated and discounted (Seale et al., 2018). This situation is further confounded by an inconsistency in presentation of these non-specific symptoms, even without alteration in the levels of CO (Sykes and Walker, 2016). The plethora of symptoms impacts diagnosis of CO exposure, as CO mimics so many other conditions (Tam et al. 2012; de Juniac, et al. 2012). Table five below summarises some of the symptoms of both conditions.

### Table 5: Symptoms of CO exposure (PHE, 2016; Pepe et al. 2011; Seale et al., 2018)

| Acute exposure | Chronic exposure |
|---|---|
| Headache | Impaired concentration |
| Nausea, vomiting and diarrhoea | Headache |
| Vertigo/dizziness | Lethargy and fatigue |
| Muscle pain | Syncope |
| Alteration in consciousness | Nausea |
| Subjective weakness | Flu-like symptoms |
| Confusion | Anxiety |
| Myocardial infarction/angina/chest pain | Psychomotor dysfunction |
| Respiratory failure | Loss of balance |
| Loss of consciousness | Changes in sleep, memory, vision |
| Seizures | Hearing loss/hyperacusis |
| Death | Emotional lability and impulsive behaviour |

## Mechanisms of harm: Oxygen starvation of tissues (hypoxia)

Cellular hypoxia causes substantial damage to those who are exposed to CO. The tissues of the body are ‘starved’ of oxygen during exposure as a result of the occupation of the inhaled CO molecule on the oxygen binding sites of the haemoglobin molecule, for which it has a high affinity. This binding reaction creates the aforementioned carboxyhaemoglobin (Roderique et al., 2015) which is the only known biomarker for CO exposure, although its reliability has never been clearly established (Veronesi et al., 2017). Carboxyhaemoglobin is known to bind preferentially with haem; it has 240-250 times more binding power with haem than does the oxygen molecule (Abdulaziz et al., 2012; de Juniac et al., 2012). It thus inhibits the amount of oxygen carried in the blood and impedes oxygenation of cellular tissue different ref (Roderique et al., 2015; Kokkarinen et al., 2014), leading to a relative anaemia (Haldane, 1972; Kao and Nanagas, 2006) and symptoms such as dizziness, breathlessness, fatigue, headaches and so on. The presence of CO also induces an oxygen dissociation curve shift to the left, thereby decreasing the ability of any remaining (unaltered) haemoglobin molecules to release oxygen to the tissues (Chavouzis and Pneumatikos, 2014). The oxygen-carrying capacity of the blood is therefore compromised (Raub, 1999) and the individual is essentially in danger of suffocation (EPA, 2010). Any oxygen within the body cannot be released to go where it is needed.

Under such circumstances, certain compensatory alterations in haemodynamic responses will attempt to ameliorate the effects of hypoxia. These include vasodilation and increased cardiac output, which would benefit otherwise healthy individuals who were breathing ambient air but may well exacerbate the deleterious effects of the CO exposure (Bleecker, 2015). However, once away from the source of the CO, binding of CO to the haemoglobin molecule reverses and oxyhaemoglobin can still be formed.

## Other mechanisms of potential harm

All of the currently available clinical data about CO exposure does not fully explain issues around damage from CO exposure occurring solely through the toxic mechanism of hypoxia secondary to hypoxaemia (Gorman et al., 2003); in particular, the causes of the delayed effects of CO damage remain unresolved. Roderique et al. (2015) are clear that this perception of the pathophysiology of CO exposure persists, regardless of “*a mounting body of evidence”* (p. 45) concerned with other mechanisms of potential harm. Instead, it can be comprehended that the way CO acts as a poison is multifactorial (Wolf et al., 2017). Research into other mechanisms of exposure and the role of CO as a gasotransmitter also continues (Roderique et al., 2015; Bleecker, 2015).

It has been suggested that the clinical effects of CO exposure may result from a combination of hypoxia and ischaemia due to carboxyhaemoglobin formation and direct CO toxicity at a cellular level (Kao and Nanagas, 2006), provoking both an immunological and inflammatory response (Chavouzis and Pneumatikos, 2014; Thom et al., 2010); this leads to injury as a result of demyelination – damage to the protective myelin sheath of nerves – of the CNS (Beppu et al., 2011). There is also a direct mitochondrial electron transfer dysfunction (Abdulaziz et al., 2012), which is essentially a poisoning of cells. Further damage to tissues also takes place due to reoxygenation/post-ischaemic reperfusion injury (Ernst and Zibrak, 1998). The combination of these effects results in a hypoxia-driven succession of complications such as apoptosis (Wang et al., 2013), some of which can be short-lived, while others are significantly more long-term (Juric et al., 2015).

CO also readily binds to several other proteins which contain haem (but are distinct from haemoglobin and also perform essential tasks in the body) and alters their essential functions (Wolf et al., 2017). These include cytochromes, myoglobin and guanylyl cyclase (Kao and Nanagas, 2006; Kondo et al., 2007), and it is considered that while carboxyhaemoglobin degenerates quickly, CO bound to these other substances will last for longer (Al et al., 2012).

Many problems can be caused by the binding of CO to these molecules. For instance, since cytochromes are responsible for oxidation and reduction reactions as necessary in the generation of adenosine triphosphate (ATP), their disruption many lead to the formation of oxygen free radicals which have long been known to have an adverse effect on normal cellular respiration (Goldbaum et al., 1975). Again, this will contribute to the fatigue, lethargy, and headaches and so on that an individual feels; binding to other proteins contributes to cardiac and other muscle pain (rhabdomyolysis) and explains issues such as incontinence (Ho et al., 2012; Rahmani et al., 2013).

There are more explanations for why the organs, particularly the heart (Tirosh and Schnell, 2016) and brain (Hopkins et al., 2006), are vulnerable to the complex complications of CO exposure (Prockop and Chichkova, 2007). Predominantly, the issue of hypoxia is relevant as both of these organs have a high metabolic rate and a significant need for oxygen (Chavouzis and Pneumatikos, 2014). CO also has a high affinity for binding with cardiac myoglobin, which consequently leads to myocardial depression, hypotension, arrhythmia and ischaemic cardiac changes (Shen et al., 2015; Akilli et al., 2013; Tirosh and Schnell, 2016) as well as disrupting cerebrovascular compensation mechanisms (Kondo et al., 2007).

The binding of CO to myoglobin, which is the primary oxygen-carrying pigment of muscular tissue, is said to occur at an even higher rate than that of haemoglobin (Harper and Croft-Baker, 2004) and can therefore lead to a reduced availability of oxygen in the musculoskeletal and cardiac systems, causing pain (rhabdomyolysis) and weakness (myasthenia). Subsequent arrhythmias, myocardial and mitral valve dysfunction (Gandini et al., 2001) and even infarction across different age-groups, including children, can therefore result (ibid). This binding also contributes to direct skeletal muscle toxicity and rhabdomyolysis (Rahmani et al., 2013).

The enzyme guanylyl cyclase is stimulated in the presence of CO. This results in cerebral vasodilation, which is linked with loss of consciousness (Kao and Nanagas, 2006). All cells in the body are therefore affected due to the metabolic consequences of the binding of CO to proteins.

In a study investigating CO’s potential to inhibit mitochondrial electron transport in the brains of rats, a process which forms part of cellular respiration, it was found that prolonged intracellular hypoxia and the resultant acidosis could be a consequence of relatively short-lived episodes of severe CO hypoxia (Brown and Piantadosi, 1992). The authors found that post CO exposure, the mitochondrial oxidation state (affected by the oxidation levels of the cytochrome cells) and metabolite responses indicate that aerobic energy production in the cortex was still impaired after near-total elimination of carboxyhaemoglobin from the blood, despite the administration of supplemental oxygen. Again, these findings may help explain the prolonged clinical effects of exposure after the decline of carboxyhaemoglobin levels (Kao and Nanagas, 2006).

## CO exposure sequelae

It is clear from the literature that those who are exposed to CO may experience negative after-effects – or sequelae – as a consequence of exposure to any concentration of CO. Although it may seem logical to think that once carboxyhaemoglobin levels have declined that anyone who is affected will recover, this is not the case. Indeed, CO toxicity may increase the brain's *"constitutional vulnerability"* to psychiatric symptoms (Ho et al., 2012 p.96), with Bleecker (2015) stating that the heart and brain may be exposed to higher levels of CO than are recorded even by timely carboxyhaemoglobin measurements. CO exposure therefore presents with a myriad of symptoms but also may be characterised, as previously mentioned, by a delayed onset of symptoms which may appear after exposure has ceased (Kondo et al., 2007). These symptoms can result in lasting and significant neurological sequelae (Hopkins et al., 2006; Department of Health, 2010) which are overwhelming and debilitating (Krenzelok et al., 1996). The onset of neuropsychiatric changes that lead to these sequelae vary from one area of the brain to another, which may have some bearing on the fact that some who are exposed may experience them immediately, while for some there may be a delay in their development. This delay can be a significant period of time (Ho et al., 2012; Hopkins et al. 2006), despite recovery apparently taking place in the interim period (Sykes and Walker, 2016).

Beppu et al. (2015) postulate that many who have experienced acute CO exposure and present with neuropsychiatric (and other) symptoms will see those symptoms resolve following the administration of oxygen. Of the remainder of this population, estimated at 30%, approximately two thirds will experience persistent symptoms, and the rest will develop a Delayed Neuropsychiatric Syndrome (DNS). Mortality is stated to be low for those receiving emergency care, the aim of which is therefore to stave off symptoms of DNS (Pepe et al., 2011). DNS is variously described as appearing over two to 40 days (Beppu et al., 2011), two to 240 days (Ho et al., 2012) or three to 240 days (Chavouzis and Pneumatikos, 2014) after exposure. As stated, symptoms can occur or recur after periods of seeming recovery (Kao and Nanagas 2006), once demyelination has advanced beyond *“some unknown threshold”* (Beppu et al., 2011 p.869).

The literature is again largely focused on acute exposure when it discusses neurological symptoms, which include memory and executive function impairment, apraxia, aphasia and agnosia, slow mental processing speed and reduced intellectual functions, lethargy, Parkinsonism, hallucinations and motor dysfunction (Hopkins et al., 2006; Prockop and Chichkova, 2007; Ho et al., 2012). A characteristic feature of this sort of delayed encephalopathy is periventricular white matter lesions (Kondo et al., 2007). MRI scans can be useful for identifying lesions in affected persons, which most notably occur in the basal ganglia/globus pallidus regions, the hippocampus, the deep white matter and frontal lobe (Yeh et al., 2014; Hopkins et al., 2006) as well as the parietal lobe (Chavouzis and Pneumatikos, 2014). Indication of such damage is manifest in a collection of conditions that may include emotional disorders, the decline of cognitive function, dizziness, paresthesia (abnormal skin sensations, such as pins and needles, burning, numbness and so on), lethargy, somnolence, motor and sensory disorders, dementia, personality and judgement disorders, encephalopathy and neuropathy (Prockop and Chichkova, 2007). In addition, as previously mentioned, pseudo-Parkinsonism also occurs, as can dystonia and acquired Obsessive Compulsive Disorder (OCD) (Katirci et al., 2011). Depression, diurnal bruxism (nocturnal grinding of teeth) and psychic akinesia (lack of affect, passivity, and apathy) (Lugaresi et al., 1990; Liang et al., 2011) may also follow, as may gait disturbance and urinary/faecal incontinence (Chavouzis and Pneumatikos, 2014).

Recovery from DNS or indeed regression of any of these symptoms is variable (Ho et al., 2012), but the prognosis may be for 50-70% remission of symptoms within a year (Chavouzis and Pneumatikos, 2014). Pepe et al. (2011) state that resolution of symptoms can occur over months but may be permanent in around 25% of cases, while Yeh et al. (2014) suggest that most people will show some improvement at six months.

## Knowledge of CO: Some history and CO's role in the body

The knowledge that CO instigates cellular hypoxia originated in the 19th century. Following Bernard's suggestion that carboxyhaemoglobin was formed in the bloodstreams of those who had inhaled CO (Reboul et al., 2012), Haldane (1895) reasoned that hypoxia would be the inevitable result of the formation of carboxyhaemoglobin. His proposal that hypoxic insult was the central issue has become the accepted explanation for CO toxicity (Gorman et al., 2003; Roderique et al., 2015). Haldane's son, however, went on to experiment with CO using the germination of cress seeds and moths as subjects. These organisms obviously do not possess oxyhaemoglobin and therefore cannot develop carboxyhaemoglobin. The younger Haldane established that moths are hindered in their movements while the rate of germination in the cress seeds was inhibited by the presence of CO (Haldane, 1927; Roderique et al., 2015). He could, of course, only speculate as to how and why those organisms were adversely affected by CO in that situation, but he did conclude that CO has a toxicity that is *distinct* from its hypoxaemic effects.

In addition, CO is produced in the body naturally as a result of the breakdown of haem (Wright, 2002; Hess, 2017). It is an essential molecule involved in normal cell functions and pathway signalling; these include vascular function, inflammation, apoptosis and cell proliferation (Hess, 2017). CO is not just an agent of poisoning but is also an important gasotransmitter (Roderique et al., 2015; Weaver, 2009) and pain modulator (Arngrim et al., 2014) and it is normal to have a low level of endogenous CO (Hess, 2017). The potential for CO to confer benefit in its actions as a molecule signaller has recently led to the beginnings of CO-based therapy for conditions such as rheumatoid arthritis (Santos-Silva, 2017; Hess, 2017). However, the presence of endogenous CO can result in a further complication when trying to establish the presence of CO exposure. Non-smokers typically have a value of carboxyhaemoglobin of <2%, while smokers' values can range between 3-12% (Chavouzis and Pneumatikos, 2014). This higher, yet normal, reading can cause difficulty in cases where chronic CO exposure is suspected. However, smokers do not experience the unpleasant, deleterious symptoms associated with CO exposure on a day-to-day basis unless exposed to additional CO (Arngrim et al., 2014). The reasons for this situation remain unclear.

## Available treatment for CO exposure

The oxygen/haemoglobin-centric theory of CO toxicity (Roderique et al., 2015) accounts for the current therapies of high concentration and/or high-pressure oxygen, which will now be discussed. As can be surmised, and as mentioned previously, the levels of carboxyhaemoglobin of an individual attending A&E will not reflect earlier levels of carboxyhaemoglobin, as time and supplemental oxygen will have contributed to its elimination (Weaver, 2009; Bleecker 2015). Oxygen therapy is commonly used, but hyperbaric oxygen therapy has long been considered a superior remedy for CO exposure (Kindwall, 1985). People being treated in this way can breathe 100% oxygen when they are placed in hyperbaric chambers compressed to greater than 1.4 atmospheres (atm) of absolute pressure (Gesell, 2008; cited in Weaver, 2009).

However, a Cochrane review of hyperbaric oxygen therapy does not defend its use for CO exposure (Buckley et al. 2011; see also Juurlink et al. 2005). Weaver’s (2009) review of guidelines for hyperbaric oxygen therapy, conversely, states that the work by Juurlink et al. (2005) showed trials that were too varied in terms of participant selection and method, and follow-up was limited. Other authors have considered the use of hyperbaric oxygen therapy (Kindwall, 1985; Clower et al., 2012; Smollin and Olsen, 2010), associating it with more favourable outcomes than normobaric (normal atmospheric pressure) oxygen therapy alone. Juric et al. (2015) state that hyperbaric oxygen therapy inhibits CO-induced apoptosis more effectively than normobaric oxygen therapy; Kao et al. (2009) report fewer neurological sequelae in those receiving hyperbaric oxygen therapy; fewer cardiovascular complications are described by Nikitopoulou and Papalimperi’s systematic review (2015) and Liao et al.’s retrospective study (2019) reports higher levels of mortality in those who did not receive HBOT. However, Pepe et al. (2011) discuss the controversial nature of hyperbaric oxygen therapy, echoing issues of inconsistencies in the way it is delivered and to whom. This is an expected consequence of a lack of universal guidelines.

In the UK, a lack of firm evidence has resulted in the NHS no longer commissioning hyperbaric oxygen therapy for CO exposure (NHS, 2018) and recommending standard or normobaric oxygen treatment instead. In other countries, the use of hyperbaric oxygen therapy is supported, albeit in a local rather than consistent fashion. Mutluoglu et al. (2016) surveyed hyperbaric oxygen therapy centres across Europe and confirmed that treatment protocols varied significantly. In the UK, at least, however, it would seem that there is little that can be offered in terms of meaningful amelioration of the effects of CO exposure other than normobaric oxygen treatment.

## Coping with the trauma of exposure to CO

This chapter now moves onto the discussion of coping with trauma in the context of CO exposure. 'Trauma' when used here always refers to 'traumatic experience', that is, psychological rather than physical trauma, unless specified. I will discuss psychological trauma, nomenclature and definitions of trauma and traumatic experience, before moving onto discussions of adaptive and maladaptive coping and coping with exposure to CO. Coping theories consider issues of why stress and traumatic experiences affect people in different ways, and have abounded in psychological and social sciences research since the 1960s. A brief description of coping is *"the thoughts and behaviours used to manage the internal and external demands of situations that are appraised as stressful"* (Folkman and Moskowitz, 2004, p.745), or mitigating or even evading harm by finding a strategy which helps to effectively manage or control the stressful event (Matthews et al., 2015). This is relevant to participants in studies such as these, where participants share in detail how they coped with the tribulations of the traumatic experience of CO exposure, and how they continue to cope with the aftermath.

## Awareness of the issues around psychological trauma

Developing an awareness of the issues around traumatic experience, or *"becoming trauma informed"* (Randall and Haskell 2013, p.501) refers to gaining an understanding of the effects of trauma on people's lives as well as the way that traumatic experiences affect their lives and futures. Trauma-informed care is certainly worthy of discussion and research, since the deleterious effects of trauma and distress on people's health (physical and mental) and well-being have become identified over several decades (Wang et al., 2019).

## Definitions of trauma, Post-Traumatic Stress Disorder (PTSD), and Complex Post-Traumatic Stress Disorder (CPTSD)

Post-Traumatic Stress Disorder (PTSD) is said to have become a *"unifying concept"* (Weathers and Keane, 2007 p.107) in the study of psychological trauma since it appeared in the Diagnostic and Statistical Manual of Mental Disorder (DSM-III) in 1980 (Frueh et al., 2012). Seemingly diverse causes of trauma exposure such as natural disaster, warfare and sexual assault and abuse, could, as a consequence of the inclusion of psychological trauma in the DSM-III, have relevant treatment developed, because their disorder was officially recognised. Disagreement has often centred, however, on what constitutes a trauma or a traumatic experience (van Der Kolk, 2003); one succinct definition is that trauma *"arises from an inescapable stressful event that overwhelms people's coping mechanisms"* (van Der Kolk and Fisler, 1995 p.505). Weathers and Keane (2007 p.108) conclude that subjective appraisal is the means by which individuals perceive events as *"ordinary stressors"* or as traumatic experiences, whether that experience is considered to be *"generally outside the range of usual human experience"* (ibid p.108) or not. Whether an experience is traumatic is therefore determined by the individual who has that experience.

Definitions of trauma are also, therefore, liable to be contested and may be a source of confusion; the word may refer to the corresponding concerns of the stressor itself (for example, being exposed to CO constitutes a trauma), a subjective reaction to that stressor by the person who has suffered it, or the acute and chronic distress that occurs as a response (Reyes et al., 2008) with the person unable to move away from the traumatic insult and subsequently suffering, sometimes greatly, as a consequence (van Der Kolk, 2003). For those exposed to CO, the nature of the symptoms and sequelae with which they may have to contend can further influence that subjective reaction and the acute and chronic resultant distress. In concurrence with Weathers and Keane (2007), for Krystal et al. (1989), it is, again, the meaning that the experience held for the individual, rather than the intensity or hazards of that experience itself, that results in the individual considering their experience to be traumatic and suffering these consequences. These consequences could include many burdensome symptoms, such as depression, psychosomatic symptoms and feelings of despair; again, such descriptions can easily correspond to symptoms and sequelae of CO exposure.

However, definitions of trauma have evolved in the medical arena, where it is treated as a disorder. For instance, the definition in the latest iteration of the Diagnostic and Statistical Manual of Mental Disorders in 2013 (DSM-V) refers to PTSD as a reaction to *"actual or threatened death, serious injury, or sexual violence"* as a traumatic experience (APA, 2013, p. 271) and so detaches PTSD from certain stressful events to which it was previously linked; a diagnosis of terminal cancer or a heart attack (myocardial infarction), whilst certainly a cause of distress, is no longer considered a traumatic experience that would cause PTSD as long as it is not immediately life-threatening. The previous version, DSM-IV, included a subjective definition of a trauma as causing *"intense fear, horror or helplessness"* (Pai et al. 2017 p.3), but the newer definition does not require these feelings to occur in conjunction with the traumatic event in order for PTSD to develop and be diagnosed (Shalev and Bremner, 2016). This perhaps signifies a move away from a more prescriptive definition, or perhaps communicates the subjective nature of those terms.

It seems, therefore, that there is a discrepancy in the definition of what constitutes a trauma as opposed to an upsetting event; it also seems to be problematic to consider truly objective measurements of PTSD as being such. Brewin et al. (2017) discuss the International Classification of Diseases (ICD-11)'s definition of PTSD and discuss the definition of CPTSD, and conclude that this measurement, also considered objective, would see more diagnoses of PTSD and CPTSD than DSM-IV or DSM-V. One key point to be considered here is that the evolving diagnostic criteria for PTSD have implications for support, treatment and therapy following a subjective traumatic experience.

There is also a further point of interest, as there is also a growing literature on the developing awareness of the relationship between the body's response to stress and resultant inflammation, depressive symptoms and *"adult neurogenesis"* (the generation of new neurons) (Baker et al., 2012, p.664). Further work in this area would enable healthcare professionals to rely on objective measures rather than the more subjective measures of the DSM-V for diagnosis of PTSD (Pinna, 2018). Essentially, biomarkers for PTSD are being identified, and this may add to the medicalised view of trauma that exists.

A trauma such as exposure to CO overwhelms coping resources (van Der Kolk, 1995) and provokes strong emotional reactions; it is the experience of the event that defines whether or not it is a trauma, rather than looking to the event itself (Wang et al., 2019). It may also be considered that the very fact of being exposed to CO, with its actual or potential propensity of causing death and its cognitive and affective impacts in survivors, could lead to the description of this experience as traumatic (Ladegaard, 2015; Randall and Haskell, 2013).

Trauma also refers to catastrophic life events, and may include physical elements such as injury (Reyes et al., 2008; Pai et al., 2017). As stated, it may be that the CO itself has caused damage to the brain, or that another physical injury has occurred, for example, Vivienne's compression injury or Tisha's hyperacusis, serving to further compound the issue. This latter is defined as a physical injury as it has been attributed to apparent damage on an MRI scan of Tisha's brain. However, even in the case of trauma without any physical injury, there can be profound effects on the body (Khamis, 2015).

Moving further away from more biomedical definitions, Reyes et al.'s (2008) definitions of the causes of psychological trauma include events that are *"emotionally shocking or horrifying"* (p. 20). They state that, as in the case of CO exposure, trauma can occur when death is threatened or witnessed, or where an individual lacks agency to prevent psychological or physical injury. Therefore, in the case of CO exposure, trauma occurs through the threat of death and harm to the individual and loved ones, and/or by experiencing the shock of losing loved ones in a sudden and seemingly needless manner. The psychological element of terror is related to the actual physical harm that CO poses, but is separate to the impact of the traumatic events – it transcends the physical (Gersons and Olff, 2005).

Trauma can be further defined as 'simple' or 'complex'. These concepts again can be likened to CO exposure. Simple trauma is the consequence of one traumatic event (such as an exposure that results in severe symptoms), whereas complex trauma comes as a result of protracted, chronic traumatic experience (Luxenberg et al., 2001, cited in Randall and Haskell, 2013). Complex trauma in particular has implications for the capacity to trust and maintain relationships (Randall and Haskell, 2013; Maschi et al., 2010). This could have significant impact on those who have been exposed to CO, in terms of, for instance, their relationships with family and healthcare professionals.

Narrating accounts of distressing experiences can help to discern the intensity of the traumatic event on the narrator. Ladegaard (2015) gives four criteria for defining what he perceives as the telling of traumatic accounts. These include crying repeatedly, some form of existential questioning (such as questioning the meaning of life or one's religious faith, or a mention of suicide), the narrator revisiting certain aspects of the trauma (suggesting that it is experienced as *"an emotionally unfinished event"* p.195) and finally, overtones of fear running throughout the narrative. Fear is also mentioned by others (Wang et al., 2019; Slavin-Spenny et al., 2011). Maschi et al. (2015) include fear and a perceived lack of control around the trauma, and consider this to be a significant risk factor for suicidal ideation.

# Effects of traumatic experience

Not all who experience trauma will develop diagnosable psychological disorders of this nature, but they may develop psychological symptoms, including mood disturbance (Macleod et al., 2016) and changes in their perceptions of themselves and the world around them (Janoff-Bulman, 1989; Janoff-Bulman and Morgan, 1994; Maschi et al., 2010). Comorbidities such as depression and anxiety are more common than not, while emotional numbing is also seen (Khamis, 2015). These symptoms also form part of the catalogue of issues that result from CO exposure itself.

Traumatic experiences are said to be commonplace and carry substantial ramifications; more people are affected adversely by trauma than is often recognised (Gersons and Olff, 2005; Randall and Haskell, 2013), which has far-reaching implications for their health and wellbeing (Maschi et al. 2010; Wang et al. 2019). People are changed psychologically when confronted with imminent, severe threat, sometimes profoundly (Khamis, 2015). Both short-term and long-term psychological issues may be present (Maschi et al., 2010) and may include *"intense anxiety, confusion, helplessness and depression"* (Janoff-Bulman, 1989 p.113). As organisms, physiological and neurological modifications occur which are said to be adaptive in the midst of the crisis (Reyes et al., 2008); the body sees these modifications as essential for the survival of the threat. According to Gersons and Olff (2005), stress disorders, of which a particularly burdensome manifestation would be PTSD/CPTSD, are a deregulation of the fear system. The threat has passed, but the stress response remains as the threatened individual cannot reorganise the fear system to recognise 'safety'. Symptoms of this disordered response include those related to re-experiencing, avoidance and hyperarousal (Shalev and Bremner, 2016). Slavin-Spenny et al. (2011) discuss what is known as re-experiencing as an intrusion, in which unwelcome thoughts and images relating to the trauma are uncontrollable. Reyes et al. (2008) state that memory issues, in common with depression, anxiety and other comorbidities (Gersons and Olff, 2015) are often found in people who have undergone a traumatic experience.

These issues also exist as symptoms and effects of CO exposure, which serves to further compound this issue.

While, as mentioned, traumatic experiences are commonplace, some known variables exist in the expression of distress resulting from the trauma. Age, for instance, plays a role in how people learn to cope with traumatic experiences through a developmental approach over the lifecourse (Maschi et al., 2010); life experiences have served to 'teach' people how to manage traumatic situations. However, some people do not develop ways of coping with trauma, for diverse reasons (Randall and Haskell, 2013). Genetic, biological and psychosocial factors also play a part in the development of symptoms of trauma, their progression and the ability to deal with traumatic experiences (Shalev and Bremner, 2016). Thompson (2019) also considers that the accumulation of many traumatic experiences over time will actually lessen any ability to cope. Gender is another variable, as women experience and report higher rates of trauma response (Jin et al., 2014). In Ladegaard's (2015) description of women's trauma narratives, he connects the trauma experience with the difficulty his participants faced in relating their accounts in a coherent manner. He cites Tuval-Mashiach et al. (2004), saying that the most striking feature of the accounts of people who have suffered trauma is that they relate *"a fragmented, partial and intensive account"* (p.203). It is generally conceded that the more marginalised and most vulnerable members of society are at more risk of severe responses to trauma (Randall and Haskell, 2013).

Traumatic stress-related changes can lead to alterations in the way people manage emotions and cognitive processes; in turn, this can change the way they cope and adjust. Goldstein (1995, cited in Medved and Brockmeier, 2004, p.477) describes a *"catastrophic reaction"* in the mind of a person suffering specifically from neurotrauma, which is relevant when considering CO exposure and its own propensity for neurological damage, separate from, but concomitant with, experiencing CO exposure as a trauma. This catastrophic reaction is a *"state of extreme confusion and disorientation* *mingled with anxiety, fear, and anger"* (ibid), which may be complicated by primary neurological damage.

There should be more prominence given to issues such as depression and anxiety following trauma; the traumatic and tragic incidents or experiences themselves, and the meaning that these experiences and their impacts have for those who suffer them, both through research and from society itself, as they shatter *"the sufferer's views about life"* (Gersons and Olff, 2015 p.1039), or similarly *"shatter a person's belief about reality"* (Khamis, 2015 p.72). An individual's concept of their self-worth, or any sense of them having agency in a largely benign world, has been damaged (Maschi et al., 2010). The world becomes less safe than it was before the trauma was experienced (Macleod et al., 2016) as previous world assumptions disintegrate (Janoff-Bulman, 1989; Janoff-Bulman and Morgan, 1994). Before a traumatic experience occurs, individuals have a belief in a meaningful world, generally believing that a moral person can typically avoid adversity. According to this set of assumptions, those who adhere to the rules and norms of society are rewarded with a safe and orderly way of life. These beliefs are not sustainable after a traumatic event which was not 'deserved' but was nevertheless endured (Wang et al., 2019). As stated, a traumatic event is overwhelming and involves the violation of the sense of *"self and security"* (Randall and Haskell, 2013 p.507).

This aspect of traumatic experience is described as *"deeply harmful"* as people may feel that justice and fairness are now not possible in life (Randall and Haskell, 2013 p.514). While it is difficult to know how many people continue to suffer with the symptoms of trauma for long periods in the aftermath of a traumatic experience, up to a third of people do not recover from diagnosed PTSD, despite treatment (Reyes et al., 2008). These authors postulate that this is due to a combination of comorbidities, stress becoming chronic, and the accumulation of both acute and chronic stress. The situation for those who have been exposed to CO is again more complex here. For some, there may be experience of exposure to CO, which they may consider to be either traumatic at the time, or they may consider the aftermath of that event to have caused trauma-related affects, or a combination of these issues. For others, trauma may have been sustained as their exposure was not recognised. Again, this struggle for recognition, as well as any aftermath from exposure, may be perceived as traumatic. Any effects of past traumatic experiences, if not resolved, may mount up; any innate coping resources may themselves be depleted by traumatic events (Lodrick, 2007; Calvete et al., 2008; Thompson, 2019). People cannot obliterate the memory of trauma (Gersons and Olff, 2005).

## Coping with traumatic experience

Ideas about coping with traumatic experience have for many years focused on the context of that experience. This concept can be traced to Lazarus (1966, cited in Folkman and Moskowitz, 2004), and his interest in viewing coping not through a lens of pathology, but in how *"ordinary people"* tackle distressing situations such as exposure to CO (ibid, p.746). Coping, as a term, can also mean different things in the literature. Lazarus and Folkman (1984) offer a definition of thoughts and behaviours used to manage circumstances that people perceive to be stressful. They developed this meaning to include change; coping is a dynamic process both in extended crises (such as a sudden bereavement, as happened to Bookie and Vivienne) or a shorter-term stressful event, in their paper on examination stress (Folkman and Lazarus, 1985). Reyes et al. (2008) state that coping is still not well researched, and can refer to the simple description of a recovery from a traumatic event to a *"more specific mechanism through which environmental and intra-individual factors influence trauma psychosocial outcomes"* (p.257). Randall and Haskell (2013) emphasise the lack of consideration given to the experience of coping with trauma in relation to social contexts and relationships. Folkman and Moskowitz (2004), however, allude to a burgeoning body of research across many disciplines; they suggest that researchers are interested in the ways that the concept of coping may help to explain why some people seem to cope with stress in a more positive way than others. The concept of coping therefore lends itself to exploring and developing interventions.

Khamis (2015), who also highlights the lack of research around coping, discusses two broad conceptual coping styles. The first looks at coping in terms of an ‘either/or’ approach; drawing on earlier work, people generally either cope in an emotion-focused or a problem-focused way (Lazarus and Folkman, 1984; Folkman and Lazarus, 1985). This two-pronged approach corresponds to the second, similar method; that of approach and avoidance coping (Khamis, 2015). Coping strategies are not consistently able to be utilised for each circumstance, however, and it is difficult for an individual to predict how effective a particular strategy will prove to be before it is adopted (Matthews et al., 2015). Lastly, Park and Folkman (1997) included a meaning-making component to ameliorate the impact of a traumatic experience, especially when that experience cannot easily be countered by problem-focused approaches.

These approaches to coping incorporate cognitive and behavioural responses, unlike earlier work that was more likely to consider a pathological process (Folkman and Moskowitz, 2004). Emotion-focused coping strategies are about dealing with the emotional responses to the stressor. This includes venting, seeking emotional support, and even disengagement from emotional responses (Littleton et al., 2007), whereas problem-focused coping seeks to deal with the stressor and includes gaining knowledge and seeking ways to ameliorate or even resolve the stressor (Khamis, 2015; Littleton et al., 2007; Folkman and Moskowitz, 2004). Emotion-focused coping is further defined as a way of dealing with emotional reactions to the stressor, rather than the processes that happen before and after such an emotional response (Littleton et al., 2007).

Khamis’ (2015) research supported the hypothesis that an emotion-focused style of coping is linked to more persistent symptoms of post-traumatic stress as well as to emotional and behavioural issues, while a problem-focused style of coping is associated with a reduction in all of these burdensome responses to stressors. This is important, as *“misplaced, counterproductive coping attempts”* (Matthews et al., 2015, p.5) can result in increased levels of anxiety as they exacerbate stress. Conversely, Littleton et al. (2007) state that this is contextual, and depends on how much an individual can control their own situation. Folkman and Moskowitz (2004) concur that coping is environment-sensitive as well as being somewhat reliant on the personality traits that influence stress appraisal and available resources for coping. Problem-focused strategies are more adaptive in situations that can be controlled to some degree; if the context means there is nothing or very little that can be controlled by the individual, such as in CO exposure, perhaps especially as experienced by those in group two, then emotion-focused strategies are more adaptive – thus, there needs to be a match between strategy and stressor. Most individuals use a variety of coping strategies (Reyes et al., 2008) and the amount of coping used can be affected by variables such as age and gender as well as the subjective nature of the event and its stressfulness (Maschi et al., 2010). Matthews et al (2015) state that individuals often learn a variety of coping strategies from experience (reinforcement), modelling behaviour on respected others, or through instruction (seeking advice), and that these strategies usually suffice for more usual stressful circumstances. Stratta et al. (2015) also emphasise the idea of a variety of coping styles being used as circumstances dictate; it is not the individual who is problem- or emotion- focused, but rather the reactions that the individual has to trauma. Discussion of the findings may reveal the extent of coping styles and strategies adopted by the participants.

Analogous with problem-focused strategies, approach strategies focus on the stressor and the reaction to it, so while emotional support may be sought, pursuing information about the stressor – in this case, CO exposure – is important, as is making a plan to cope with the stressor (Snyder and Pulvers, 2001). This is contrasted with avoidance, in which a person withdraws and disengages, avoiding the stressor (Littleton et al., 2007). This distancing may be beneficial in the immediate aftermath (Folkman and Moskowitz, 2004), but is considered maladaptive in the longer term (Snyder and Pulvers, 2001). Park and Folkman (1997) suggested a meaning-making factor; individuals employ values, beliefs and goals to ameliorate stressful reactions, particularly when that stress is ongoing. A coping style may assist an individual or put them at higher risk from persistent and negative issues resulting from the trauma (Maschi et al., 2010).

# Coping resources, skills and resilience

Coping resources are *"protective reserves"* that allow individuals to manage traumatic experience more effectively and recover more successfully, and include individual and social domains (Maschi et al., 2010 p.381; Thompson, 2019). Social support, often in the form of social relationships and social connectedness, is recognised as important for helping to manage traumatic experience (McDonough et al., 2011; Thompson, 2019). Social support and a problem-focused coping style significantly predict self-efficacy in traumatised individuals (Stratta et al., 2015).

Resilience, which is the capability to endure and recover from trauma, is considered crucial in issues of trauma (Thompson, 2019; Randall and Haskell, 2013). Both coping styles and coping resources can be defined as a set of skills; resilience is said, therefore, to be the result of the implementation of those skills (Stratta et al., 2015). Coping approaches which recognise and foster resilience are therefore seen to be more effective (Randall and Haskell, 2013) and to have the ability to ameliorate the severity and duration of negative psychological symptoms (Stratta et al., 2015).

Viewing issues around trauma through the lens of mental and emotional wellbeing, that is, the pathogenic view of trauma (Dekel et al., 2011) leads to a tendency, as discussed, to focus on disorders such as PTSD as well as a consideration of reactions to trauma as being 'disordered' if they do not adhere to recognised histories. In contrast, narratives that look at trauma as defined by the person undergoing that trauma can inform us of what that experience was like. As stated by Folkman and Moskowitz (2004), in the dynamic process of coping, *"retrospective accounts … may be telling us what the person is doing now to cope with what happened then, as well as what the person did then to cope with what happened then"* (p.751). Accounts can be disorganised in their structure, however, and have been described as *"broken narratives"* (Hyden and Brockmeier, 2008 p.1), and are characterised by a difficulty in articulation as well as a *"traumatic gap"* (ibid, p.16) between the experience and the language at our disposal to explain that experience. Trauma is injurious and debilitating; however, telling an account of the trauma may help people regain a lost voice

(Ladegaard, 2015). In a similar way, exploring the experiences of people who have been exposed to CO must be told from the perspective of those individuals, and those individuals have to be able to talk about what is important to them about the experience, rather than focusing on specific symptoms caused by exposure to CO. By so doing, knowledge of this condition will expand and those who suffer exposure are more likely to have access to appropriate support. One hope is therefore that preventable tragedies, such as exposure to CO (Ghosh et al. 2016) may be avoided; another is that research which includes coping as a subject area may add to the body of knowledge about coping. Folkman and Moskowitz (2004) postulate that such work can be used to design interventions which will be helpful to individuals coping with stressful and traumatic experiences.

## Traumatic bereavement

Bereavement is a difficult yet all too familiar event. Grief at the loss of a loved one is a personal issue; Kubler-Ross (1989) and Bowlby (1980) have both contributed well-known stages of grief theories which map out the broad progress of grieving and adjusting to life without the deceased person. Pain is a clear characteristic of any kind of grief and is accompanied by practical changes as survivors adapt to their new day-to-day lives without their loved ones.

The term traumatic bereavement, however, denotes the loss of a person who has close personal significance through a traumatic situation (Reyes et al., 2008). This experience can leave the bereaved feeling completely overwhelmed by sudden, irreparable loss (Barlé et al., 2017). The bereaved person’s experience consists of the event itself, and frequently of eidetic pictures of the person who has died in that situation, while the usual course of grief can be interrupted with subsequent symptoms of trauma (Malkinson and Brask-Rustad, 2013). Reyes et al. (2008) also discuss a prolonged grief disorder that is sometimes termed as complicated grief. This can occur when the bereaved person finds that the loss is overwhelming, or if they are embittered about the loss and have *“significant dysfunction in management of life tasks”* (ibid, p.75). In many cases, the grief experienced by those who have suffered a traumatic loss is more severe, all-encompassing and lasts for longer than for those bereaved by a more expected loss (Barlé et al. 2017). Being unable to find any meaning in a loss has been linked to the development of a complicated grief disorder (Holland, Currier and Neimeyer, 2006). Other disorders such as depression, anxiety and PTSD may occur simultaneously with difficulties in grieving. For some people, this is because of the loss, rather than the trauma, or may as a result of those disorders being already present (Reyes et al., 2008).

## Summary

This section has discussed the nature of CO and the effects of exposure, and the nature of the literature about CO. It has established that the presence of a single biomarker, carboxyhaemoglobin, is all that is available to establish whether an individual has been exposed to CO. It has also made clear that presence or absence of this biomarker does not completely represent the situation. I have used scientific data and language to reflect the biophysical/biochemical academic literature and explain the complexities of CO and the effects it has on people; a necessity to provide background and context to the thesis. All aspects of the subjective experiences of the participants in this study will be discussed in later chapters.

The chapter then went on to summarise some of the relevant literature around trauma and coping. Trauma and traumatic experience are terms that have somewhat different, subjective meanings in that literature. Traumatic experiences are common, however, and have substantial implications for the health and wellbeing of those who undergo them. Coping is a dynamic process, requiring resources such as resilience and the ability to make or find meaning in a traumatic experience. The following chapters introduce the methodological considerations in this research.

# Chapter three: Theoretical background and IPA in CO exposure

## Introduction

In this chapter, I will explore the theoretical foundations and background to this IPA study. As Willing (2008) states, researchers who lack philosophical training can access a phenomenological methodology through the use of IPA; this may have contributed to the view that IPA does not necessitate the involvement of *"complex theoretical issues"* and is thus *" 'easy to do' "* (Shinebourne, 2011 p.16; author's punctuation). This assessment has been highlighted and perhaps reinforced by the views of writers such as Giorgi (2010) and Sousa (2008); further criticisms of IPA are detailed below. Exploring the theoretical framework, however, allows readers to conceptualise research in a broader context and provides a supporting configuration for methodology, methods and analysis. Grant and Osanloo (2014) correlate this framework with the vital blueprints needed for building a house; without this underlying plan, the whole structure and vision is indistinct.

I will explore the rationale for the choice of IPA and will examine the three philosophical tenets that underpin the method; phenomenology, hermeneutic inquiry and idiography. The importance of reflexivity and, as stated, criticisms and limitations of IPA will also be covered, as will the limitations of the study. I will follow Staller's (2013) logical integration of the relationship between ontology, epistemology and theoretical perspective as well as methodology and methods, in addition to exploring the ways in which these notions have informed the research and are manifest in this study. Staller's final concept of *"method"* (2013 p.404), as she travels from the most abstract to the most *"concrete action step"* (ibid, p.403) will be discussed in the next chapter of that name. Throughout the section, I have alluded to some of the differences in terminology around this area used by different philosophical perspectives.

## Reflexive pit stops

It will be apparent to the reader that reflexive pit stops in the form of text boxes have been scattered throughout the work (Crimmins, 2018). This device presents excerpts from my reflexive diary. It is hoped that they will illuminate some of the reflexive thought processes with which I engaged whilst generating data and throughout its analysis. The importance of reflexivity as a practice, in both hermeneutical inquiry and in IPA, will be explored in a later section of this chapter. Initially, I will present again the research questions and some information about the qualitative research approach.

## Qualitative research, IPA, and the aims of this research

The qualitative research approach of this study investigates what it is like to undergo exposure to CO and to live with the aftermath of that event. The research questions underpinning this thesis, as stated in the introduction are:

- What is the experience of people who are exposed to CO?
- How does the exposure affect their lives?
- How do they experience the aftermath of that exposure?

Qualitative research as employed in IPA places an emphasis on subjectivity, authenticity and allowing the participants' voices to be heard (Silverman, 1993; Larkin et al., 2006), aims which are also the central features of my own research. There is an idiographic, or individual understanding that develops from participants' accounts of what their experience means to them, within their social contexts, living with the particular circumstance of exposure to CO (Biggerstaff and Thompson, 2008; Shaw and DeForge, 2014).

A qualitative approach which concentrates on and gives meaning to participants' insights, in order to capture *"routine and problematic moments and meanings in individuals' lives"* (Denzin and Lincoln, p.7, 2013; Mason, 2007) is therefore crucial. Research that is qualitative in nature accesses participants' experiences in what Banks (2007) calls their normal environments, in order to gain that deep understanding and rich data acquired through the subjective experience of individuals. It refrains from producing a well-defined theory of what is being studied and does not seek a 'truth' or generalisable points from the interpretation of participants’ accounts (Smith, 2011a; Shaw and DeForge, 2014). It is clear that this reference to a ‘normal’ day-to-day environment refers to the juxtaposition of being in a laboratory setting, which is where subjects of psychological research of a quantitative nature may find themselves, and where little about experiencing exposure to CO could be understood.

As stated by Wright and Losekoot (2012), phenomenological research occupies the end of a spectrum away from positivistic, nomothetic or quantitative research, which is deductive and objective in nature and where reliability and validity can be demonstrated and results will be quantifiable (Creswell, 1994). Phenomenological research is, therefore, inductive and subjective and aims to perceive the complex reality of what is being experienced.

## Paradigm

When denoting diverse notions around qualitative and quantitative research, different scholars use the word ‘paradigm’ in diverse ways (Staller, 2013). Originally, the term paradigm was concerned with a central set of beliefs, suppositions and assumptions which define the nature of the world and the place of individuals within that world (Kuhn, 1962, cited in O’Reilly and Kiyimba, 2015) as well as shaping how the researcher perceives the world and operates in it (Denzin and Lincoln, 2013). A paradigm also therefore determines the ontological, epistemological, axiological and methodological premises of the work (Corbally and O’Neill, 2014; Denzin and Lincoln, 2013). It is an interpretive framework considered to be a fundamental set of beliefs which directs any and all actions of the researcher. A paradigm must therefore address the aims and objectives of each study in order to inform and guide the taken approach (Guba and Lincoln, 1994). Phenomenologists seeking to illuminate lived experience therefore need to adopt a paradigm which captures that phenomenon and serves it well (Finlay, 2014).

Biggerstaff and Thompson (2008) consider that qualitative paradigms allow researchers to develop and present an understanding of what it means to undergo a particular experience, enabling illumination of the complexities of bio-psycho-social phenomena in order to improve practice, especially in the area of health care. The paradigm or interpretive framework used here is therefore constructionist, in that it assumes a relativist ontology and a subjectivist epistemology, in which the 'knower' (the participant) and the 'respondent' (myself) work together to create meaning from each participant's experience as someone who has been exposed to CO (Polkinghorne, 1992; Denzin and Lincoln, 2013), rather than my seeking any objective, common 'truth' about CO exposure that awaits discovery (Shaw and DeForge, 2014). The paradigm is concerned with the comprehension of how a person is positioned in the world (Van Deurzen, 2014). Rather than the ontological position which assumes that the world is objective and that 'truth' can be discovered, this research considers that the world is socially constructed, and 'truth' is subjective (Shaw and DeForge, 2014).

## Ontology, epistemology and methodology

Establishing an ontological position in any research can be deemed an important beginning, since ontological inquiries are concerned with the nature of reality and what can be known about the 'real' world; they are concerned with questions about the nature of truth and ways of being considered (Staller, 2013). Lysaght (2011) stresses that the choice of theoretical framework should echo and reveal personal beliefs and understandings about knowledge (Grant and Osanloo, 2014). Reflexive consideration of ideas about how the nature of reality is conceptualised (O'Reilly and Kiyimba, 2015) reveals that rather than a realist perception (that is, the idea that a reality exists regardless of people's beliefs and understanding of it, and that researchers merely have to find a way to reveal this 'true' reality), I take a more relativist stance. The world is only known and knowable because people interpret it as such, through constructs. If there is a 'reality' to be accessed and measured, the only way that people can access this reality is through their own unique interpretations of the world, none of which are any 'truer' than any other (Ormston et al., 2014;

Chen et al., 2011). People who have been exposed to CO have all had their own individual experiences of that exposure; reflected and included in that experience are their individual contexts and socio-cultural histories which will be a fundamental part of their accounts and experiences.
The research is also, therefore, idiographic. This denotes the ontology that events are specific and unique to an individual, where the lived experience of CO exposure and issues which are unique to the individual and their specific context are at the centre of the research, and where results are therefore not generalisable, cannot be measured and are *"difficult to appreciate through sensory observation"* (LeVasseur, 2003, p.408).

Epistemology raises issues around the nature of, or about, knowledge (Staller, 2013), asking how we know what truth is, and what the relationship (if any) is between the knower and the known (Guba and Lincoln, 2004). As the communication between myself and the participant is the vital means of knowledge production throughout this research, my epistemological position will affect this communication, so again, it is important that I consider the issue. Smith et al. (2009) assert that, for IPA, epistemology is a *"conceptual issue with a practical impact"* (p.46). IPA is guided by a specific worldview and epistemology, and is thus not 'simply' a methodology (Eatough and Smith, 2008). This epistemological standpoint holds that meaning was created *between* the participant and myself as the researcher, which corresponds with the aims of IPA; any pertinent personal values (axiology) that I hold should therefore be acknowledged to ensure they are not undetected and potentially become vehicles for any form of bias. This last point is closely related to the need for reflexivity in an IPA study with its emphasis on a hermeneutic, circular approach (see below) as well as how any ethical considerations are managed (see next chapter).

Finally, Polkinghorne (1992 p.218) links methodology to *"the epistemological theory that informs the use of particular research methods".* Staller (2013) defines the term methodology as referring to comprehensive research design, as opposed to methods, which are stages in the research process, such as data generation and sampling. These methods must be presented collectively and logically in an intelligible and comprehensible form, since individually they are incohesive when they are not connected to epistemological and methodological frameworks.

## Symbolic Interactionism: A theoretical perspective

Staller (2013) discusses the disparities that exist between different approaches to scholarly thinking and the required acceptance that scholars disagree about epistemological matters. For Crotty (2003; cited in Staller, 2013, p.405), a theoretical perspective is *"directly related to the theory of knowledge"*; this is what Hesse-Biber and Leavy (2004) would term an epistemology. These latter authors are, says Staller, making a distinction between a theory of knowledge and a theoretical lens; taking a different perspective, viewing matters through a different lens, can help us to understand aspects of the social world, or the context in which these participants operate.

Symbolic interactionism aids interpretation between researchers who are interested in the meaning of events and those experiencing them (Wright and Losekoot, 2012). Interpretation through the symbolic does not lead to *"any straightforward sense of empirical reality"* (Plummer 2001, p.*xi*), and thus aligns with the ontological and epistemological standpoint of this research.

It was interesting to see, during analysis, how Ajay reacted when he was 'expected' to use a wheelchair during his hospitalisation. He was ill from exposure and had a long walk through corridors ahead of him; many people in this situation would have followed what is, in effect, the social norm of using the wheelchair and allowing themselves to be pushed. For Ajay, a wheelchair was not just a mode of transport. It was a symbol of his incapacitation, if he used it; not using it therefore became a symbol of triumph. Whatever CO had done to him, he was going to emerge victorious and he saw himself as controlling that; the wheelchair was so symbolic that it was worth 'breaking the rules', ignoring how his body felt and insisting on walking unaided.

The term is credited to Blumer (1969). According to symbolic interactionism, people are creative agents (Eatough and Smith, 2008) who draw meaning from social interaction; they then act towards entities based on the meaning those entities have for them. Such interactions are always mediated and conditioned by the environment (Smith, 1996; Denzin, 1995). The actor has the ability to constantly interpret the social world and modify that meaning; 'truth' and 'reality' are therefore created by action and interaction, and people develop a sense of self through interpretation of their symbolic interactions (Eatough and Smith, 2008). Interactions are realised through symbols; a role may be symbolised through a uniform, for instance, whereas water can be symbolic of such diverse notions as life, introspection and/or freedom and often reveals a deeper, symbolic meaning in literature (Arikan, 2014). Human experience can thus be viewed through the lens of symbolic interactionism as *"dynamic – constantly flowing and changing, as interactions multiply and new layers of symbolism are added"* (Thompson, 2019, p. 43, author's emphasis).

For IPA researchers, data are words. Language *per se* can be problematic, since words can construct as well as reflect experience (Willig, 2013). As sense-making creatures, people exist in frameworks of meaning-making where experience is *"woven from the fabric"* of our relationships and contexts (Smith et al., 2009, p.194). I cannot separate these things; I cannot directly access another's experience and nor can I interpret or make sense of that experience without my own contextual understanding (Smith, 1996). IPA's meaning-making is therefore inextricably tied into the contexts in which people live their lives. Eatough and Smith (2008) see symbolic interactionism as a theoretical perspective or lens for IPA (Staller, 2013) with which to view that meaning-making, as both are strongly concerned with the nature and meaning of lived experience (Plummer, 2001; Smith et al., 2009).

## Rationale for using IPA to explore issues of CO exposure

IPA is considered suitable for examining experiences that are complex, and are neither previously investigated nor well understood (McCormack and Joseph, 2018), such as the lived experience of exposure to CO. Brocki and Wearden (2006) explore the specific application of IPA, stating that a substantial proportion of this research is concerned with health-related subjects. Over time, greater understanding of people's experience of illness has seen a move away from a straightforward biomedical model of disease towards a more constructed portrayal of illness and what it means to be ill. It is recognised that people have individual and important perceptions of these experiences and their meanings. In this area, where there is no literature concerned with CO exposure from the perspective of those who have been exposed, IPA affords the opportunity to bring the complexities of this experience to light. IPA is necessary for examining people's lived experience of CO exposure while ensuring that this subjective account with its appropriate theoretical framework is adhered to. As stated, this is not a researcher-driven, positivist investigation that looks at causes and effects of CO exposure (McCormack and Joseph, 2018).

## IPA's philosophical foundation

IPA is the product of a number of styles of thinking developed by separate philosophers; in particular Heidegger, Husserl, Merleau Ponty and Gadamer (Smith et al., 2009; O'Reilly and Kiyimba, 2015). Each of these thinkers has a different, complementary emphasis. Husserl was concerned with the internal psychological processes of the individual, whilst Heidegger was more focused on existential matters. Merleau-Ponty, too, was absorbed with being in the world; while Heidegger (1962; Blattner, 2006) was concerned with emphasising the worldliness of existence, Merleau-Ponty (2002) concentrated on the embodied characteristics of people's connection to the world. He saw our bodies as our way of communicating with the world, rather than as objects in the world (Smith et al., 2009; Larkin et al., 2019). IPA can therefore be seen to be concerned with human lived experience. It is especially useful in this context of CO exposure, as any previous research on this topic has focused primarily on what can be objectified as facts (Wawrziczny et al., 2014) or, in this context, symptoms that have been previously linked to exposure (see chapter two) from the perspective of the healthcare professionals who cared for them, rather than an individual's own subjective account of how they give meaning to the experience of exposure (Smith and Osborn, 2007).

## Phenomenology

In accordance with Koch (1995), contextualising phenomenological research to the philosophical traditions that inform its methods is crucial. Since the borders between concepts are fluid and open to interpretation, difficulties and tensions can arise (Staller, 2013), and different perspectives on ontological and epistemological positions have led to different approaches and frameworks being used in qualitative research (Ormston et al., 2014). One such approach, which is particularly relevant to this study, is phenomenology itself, which encapsulates the previous discussions on the stance of this research as a way of thinking that stresses the need for researchers to gain knowledge of their participants' worlds from the participants' perspectives. This is, fundamentally, seeking knowledge on what it is like to experience being human (Smith et al., 2009) and how people make sense of the world around them (O'Reilly and Kiyimba, 2015). This is the first of the tenets of IPA.

The phenomenological approach has sought to critically challenge and overcome the Cartesian dualistic world view, where all is split: mind/body, person/world, subject/object (Eatough and Smith, 2008; Polkinghorne, 1992), a world view that is the foundation of much positivist work. The separation of mind and body results in the comprehension of bodies and life itself as mere biophysiology (Murray and Holmes, 2014), rather than an understanding of a body that is situated in the lifeworld, which can be defined as *"the taken-for-granted, everyday life that we lead"* (Smith et al. 2009, p.15; Husserl, 1970). Phenomenology centres on the *"content of consciousness"* and the individual's experience of their lifeworld (Willig 2013, p.54). IPA is phenomenological in that it seeks to convey individuals' subjective ideas or personal perceptions about their experience, rather than to devise objective accounts of that experience (Brocki and Weardon, 2006; Smith et al., 2009; Smith, 2018).

Husserl is considered the founder of the phenomenological approach (Dowling, 2005; Polkinghorne, 1992). He argued that the 'reduction' or 'epoché' is necessary for this approach (Finlay, 2008). The researcher who adopts this position must 'bracket' or attempt to set aside what is already known about the phenomena (Willig, 2013). According to phenomenology, in order to *"go back to the thing itself"* (Husserl, 1970 p.128), I would need, to a greater extent, to suspend or bracket my view of the world and my natural interpretations or pre-understandings (Finlay, 2008) for the phenomenon to *"show itself in its essence"* in the account of the participant (Finlay, 2014 p.122). However, IPA is about making meaning between participant and researcher, and excluding my own position would not be wholly achievable (Relles, 2015); it can be assumed that social, cultural and political dynamics are always present between participant and researcher (Lincoln and Guba, 1985; Richards and Emslie, 2000). Therefore, from a phenomenological position (and through the lens of symbolic interactionism), one cannot think of subjects and objects as separate from our experience of them – their manifestation as a particular item or concept signifies their reality at any given time (Willig, 2013).

## Hermeneutic inquiry

Heidegger's use of a hermeneutic lens of cultural and socio-historical meaning (Eatough and Smith, 2008) through which to view and illuminate the phenomenological perspective was vital to his philosophy. As a result, hermeneutic phenomenology has become associated with his name. Originally an interpretation of religious and other texts, the term 'hermeneutics' is often now used to refer to general interpretation. It is also wide-ranging and expresses a range of different perspectives (Smith, 2011); Willig (2017) has articulated this as a spectrum. Within the process of IPA there exists a two-stage or double hermeneutic (Lyons and Coyle, 2007; Smith et al., 2009) which involves the participant endeavouring to make sense of their experiences while the researcher is trying to make sense of the participant's sense-making. Hermeneutic concepts also illuminate the dynamic relationship between part and whole; to understand one, it is necessary to also understand the other. This allows for a non-linear way of thinking, in which, for example, the meaning of the individual interview becomes distinct when seen from the context of the entire research project. Any understanding of any part of the text or data requires understanding of the meaning as a whole, which can indicate that that the social and cultural context in which the data collected is crucial (O'Reilly and Kiyimba, 2015; Larkin et al., 2008) and researchers must take this holistic approach (Bryman, 2008). Bryman (ibid) affirms that hermeneutics have been instrumental in the development of interpretivism as an epistemology, where interpretation of the participant's account is central. Polkinghorne (1992) suggests that hermeneutic interpretation is necessary for the study of human experience, and that the contention is based on the *"human realm"* (p.220) and its constituent meanings; any examination requires interpretation in order to lead to understanding and cannot remain un-interpreted (Smith, 2011a). In addition, all interpretation, such as that employed by IPA, seeks to augment meaning (Willing, 2017). IPA thus suggests that experience can be comprehended, understood and interpreted through examination and exploration of the meanings that people give to it (Smith, 2011b).

This is reflected in Heidegger's hermeneutic phenomenology, which is concerned with the intersubjective qualities of Being; our engagement with the world is always through interpretation (Gee, 2011). The term intersubjectivity refers to the inter-relational nature of our lives and engagement and situation in the world. Research utilising phenomenology and hermeneutics is therefore concerned with what happens 'in between'; in between people and others around them, whatever their relationships, in between people and objects, and people and cultures (Larkin et al., 2019). Intersubjectivity is a concept which has the purpose of capturing this relatedness, so that people can make sense of the world (Smith et al., 2009). Being-in-the-world is always from a certain perspective and chronological viewpoint, and is always in-relation-to something (Blattner, 2006); it is necessary to incorporate this into any interpretation of phenomena. The concept of the body and the lifeworld, therefore, is offered as a critique of the Cartesian dualistic perception that separates and favours the agency of the mind over the materiality of the body (Blattner, 2006).

This is also clearly linked to the previous discussion regarding views of reality and illustrates how complex it can be to disentangle these conceptions around, for example, Glaser and Strauss' notion (cited in Staller, 2013) of an *"exact picture"* (ibid, p.409) of the studied world that could be revealed through exploration. This notion has been deemed to be more of a realist, objectivist epistemological viewpoint (Staller, 2013; Varpio et al., 2017). Other ideas around the interpretation of such a world are more relativist and constructionist. For instance, Charmaz (2006 p.10) credits any *“theoretical rendering”* within grounded theory as interpretation. As previously mentioned, in the former worldview, researchers uncover a reality that is already present, while in the latter, constructionist perspective, researchers play an active part in interpreting and constructing (Staller, 2013), as they do in IPA studies.

As stated by Brocki and Wearden (2006), people come to interpret and understand their world by articulating their own authentic narratives into a form that makes sense to them. IPA thus seeks to use the assumed impulse for self-reflection that is common to us all as sense-making creatures (Smith et al., 2009). Hermeneutic inquiry thus provides insight into an individual’s intimate experience of body and illness, psychological distress, and personal identity (Murray and Holmes, 2014) following an event such as CO exposure.

Another way of perceiving the double hermeneutic and the process of interpretation therein is Ricoeur’s stance on hermeneutic enquiry as a hermeneutic of empathy and a hermeneutic of suspicion, said to be complementary types of understanding as neither can engender adequate insights individually (Willig, 2017). A follower of Husserl rather than Heidegger, Ricoeur positioned himself within ‘methodic’ hermeneutics (Jervolino, 1996), where he discusses the terms under a broader hermeneutics of praxis. Smith et al. discuss the hermeneutic of empathy as examining the experience *“in its own terms”* (2009, p.36). A hermeneutics of suspicion, however, not only invites the use of theoretical perspectives from other disciplines to further explore the phenomenon, but engages with the examination of participant accounts to examine possible reasons as to why a participant expresses themselves in a certain way that therefore construes a certain meaning. Willig (2017) stresses the top-down approach of this employment of hermeneutics, engendered as it is, from a ‘suspicious’ attitude, stating that the researcher should make sense of phenomena such as CO exposure by identifying the hidden, underlying constructs which generate them; this has the effect of positioning the researcher as an expert with *“privileged access to the meaning of the phenomenon”* (p.5). This, however, is in contradiction with the notion of acknowledging participants’ voices and implies an imposition of meaning, and is in contrast with empathic hermeneutic interpretations which progress from the bottom-up and therefore emphasise the participant voice. For these reasons, I have sought to present the hermeneutics of empathy in this research.

As discussed by Smith et al. (2009), however, IPA occupies a central position between these two stances of empathy and suspicion. This central position deems interpretative work to be appropriate on the condition that it *"serves to 'draw out' or 'disclose' the meaning of the experience"* (p.36 authors' punctuation), and means that, for Smith et al. (2009), interpretation, or the process of searching for understanding, within IPA can be both empathic and also employ a hermeneutics of questioning, which differs from Ricoeur's hermeneutics of suspicion. In addition to adopting the *"insider perspective"* (p.36), the interpretation also becomes more dependent on my interpretations of the data, and interpretation strives to bring together the understanding of the participant and researcher.

## Idiography

Idiography is the third major influence on IPA. It has a commitment to the particular (Smith 2011) and is related to the individual, unlike nomothetic research, which is concerned with determining general principles of human behaviour by making claims regarding groups or populations (O'Reilly and Kiyimba, 2015). Idiographic methods are concerned with human emotion, thought and behaviour – the messy, chaotic features of people's lives – with the expectation that a deeper understanding of the phenomena under investigation will be reached (Eatough and Smith, 2008). According to Smith et al. (2009), this commitment to the particular works at two levels in IPA; firstly, in the sense of the detail and depth of the analysis, which must be thorough and systematic, and secondly, in the method's commitment to understanding how particular phenomena have been comprehended by particular people in particular settings. This is why IPA studies often use small, purposive samples, as has been done here, and may use single case studies. The term commitment, incidentally, involves demonstrating prolonged engagement with the research topic and is related to the wider discussion on the evaluative criteria for qualitative research (see below; Smith and Eatough, 2007).

## Reflexivity

Whilst engaging with the double hermeneutic, where I am making sense of the participants' sense making about their experience of being exposed to CO, it is vital that I also undergo a process of reflexivity. This positionality (Shaw, 2010) of understanding as a researcher 'where you are' in the research requires that I recognise some of my usual positional interactive habits. As stated by Koch (1995), and echoing my constructionist position, it is not wholly possible to achieve a detached standpoint as data is interpreted data; the phenomenological reduction cannot be fully employed. Engaging in reflexivity can be an active and challenging process. However, reflexivity is essential in order to become self-aware about the difficulty of separating the *"object of knowledge"* from the *"knowing"* subject (Shotter, 2014, cited in Givropoulou and Tseliou, 2018 p.126). In this way, a researcher is able to more clearly see any influences from their own personal or professional background that have the potential to affect data generation or data analysis (Clancy, 2013; Richards and Emslie, 2000). It is therefore closely connected to issues of quality and ethical concerns in IPA. Reflexivity can be seen as an active process in which I reflect on my own experiences and how they influence the construction of the interactional context (the data generation during interview) and the later interpretation of the data (Shaw, 2010). Rather than just thinking or reflecting about the self (Schon, 1983), reflexivity provides a space in which my *"inseparability"* from participants' experiences can be acknowledged and considered (Givropoulou and Tseliou, 2018 p. 126) along with the stages of the research process (Richards and Emslie, 2000). It is a dynamic process (Finlay, 2008a) which occurs both instantaneously and iteratively.

Finlay and Gough (2008) affirm the difficulty of 'doing' reflexivity and the challenges in reaching a definition of the concept, with Finlay's discussion remaining focused on the *"value of examining the research relationship"* (2008 p.10). Reflexivity is a proactive and *"explicit evaluation of the self"*

(Shaw, 2010) which encompasses ways of questioning attitudes, thoughts, reactions and habits as well as the effects of these things on experiencing and interpreting participants' accounts. This can never be fully evaded (Mauthner and Doucet, 2003).

With regards to phenomenology, a reflexive approach will not limit the influence of pre-understandings but may highlight any that are present. Without reflexivity, there is a possibility of research being dominated by the personal qualities and biases of the researcher, without any recognition of what those factors are (Underwood et al., 2010).

## Reflexivity in this study: My position

I identified myself as having a nursing background (although I am no longer practising) in the initial communications with the participants, as this seemed, to me, to be an ethical issue; as previously stated, reflexivity is linked to axiology, in which the values of the researcher inform the design process of the study (O'Reilly and Kiyimba, 2015).

Initially, this openness was undertaken to facilitate rapport between myself and the participants; people are rarely embarrassed about telling nurses the specific details of what happened over the course of any episode of ill health. Incontinence is a common occurrence during CO exposure, for example, and I wished for any participant to be comfortable enough not to be anxious or embarrassed if that had been part of the experience that they wanted to share (as turned out to be the case several times).

Nursing still forms a large part of my identity, it would seem, even without setting foot on a unit; it certainly is there in many pre-understandings. My research interest in this area was initially ignited by the health aspect, which has remained a strong part of the whole; the question remains, if I had not revealed this about myself, would the data generation differ? In some ways, I'm wrestling with this – can I be subjective, can I get at intersubjective meanings so that we can co-create something here, or am I always (nearly unconsciously) 'looking' for a symptom or an effect that I can make a 'biological sense' from? And what difference does that make, as long as I keep 'aware' of it? When Kate talked about her fibromyalgia (the diagnosis of which came a while after her CO exposure), I was conscious of a few simultaneous and later impressions – she asked if it happened to others, and I thought, I don't know enough about CO, let alone the condition; but I know it's still a bit of a 'questionable' diagnosis to some people, which might make it harder for her to have a voice about her exposure (and there is also stigma for her to contend with about such painful/invisible/contested things with perhaps some 'subjectivity' in its expression); and, nah, it was years after your exposure, how can that be linked?(!) Kate might have asked what everyone else was experiencing, but she might have framed it differently for the 'woman from John Moores' than 'the nurse'.

Conversely, I did think about not telling participants about my background and just appearing as a 'researcher'. The possibility exists that giving that information pre-disposed the participants to think about the health-related aspects of their experience before anything else, whereas I wanted them to present what was important to them about the experience (Richards and Emslie, 2000).

Inherent power dynamics between the researcher and participant must always be acknowledged (Bolderston, 2012) as part of the reflexive process. While nurses are perceived as empathetic to the suffering of others (Clancy, 2013), they could also be seen as authority figures, which would not be conducive to participants' standing as the expert of their own account (McCormack and Joseph, 2018). Such dynamics can affect the interview, for example by causing issues with openness, and can be difficult to identify. These participants generally saw me as willing to listen and trying to understand, and they mostly found that my position as an 'insider' with some relevant clinical knowledge (Burns et al., 2010) beneficial; some asked questions about CO exposure, for example; they were interested in what I had read and understood about CO exposure symptoms and sequelae. Through reflexivity, I realised that my professional background had other uses. As a nurse, I was perceived as being able to understand what participants had had to endure; both from the point of view of their symptoms and from the point of view of being an 'insider' in UK health care systems. Participants talked about negative and positive experiences with healthcare professionals, including nurses. While I hoped I was perceived as neutral from this perspective, as someone no longer directly connected with the NHS or without any effect on any power dynamic between them and the healthcare professionals involved in their care, this is a difficult position to claim with any certainty (Richards and Emslie, 2000). There was also the

Showing my pre-understandings: Bookie was very relieved when I told him that his difficulty with controlling his temper and the way he spoke to some people (and he was certainly provoked) could have his CO exposure as a contributing factor. He'd never come across this information before. How much did my telling him his affect the rest of his account? There is no way of knowing, really, what he expected me to know about CO and he hadn't talked of it before we met. I made the decision to wait until the end of interviews before talking about my thoughts on things like CO symptoms and effects in case my 'knowledge' and preunderstandings had any impact on Bookie's story; in the event though, I changed my mind. The interviews were a participant-led conversation and the flow of that is important for co-creation of subjective meaning. Perhaps it is not the role of the researcher to 'tell' participants about their 'condition' and give reasons, but it was 'of the moment'. Rapport, I think, was enhanced by natural communication, and 'normalising' is a typical conversational activity.

concomitant danger that a participant might assume that I understood an issue that I did not, and therefore may not have alluded to it fully (Simmons, 2007). Kate mentioned a condition that I had not heard of before, but asking her to explain it did not interrupt the flow of the interview.

My reflexive diary has been invaluable to me throughout the research, as evidenced in the reflexive pit stop text boxes present in this chapter and the rest of the thesis. The recording and subsequent reviewing of thoughts and observations before and after interviews (especially the recording of the immediate impact of interviews) as well as throughout analysis allowed for some meaningful and difficult questions to be confronted. The diary allowed me to stand back from my understanding of the world and helped me to see how and why I was making certain interpretations of the data.

## Quality in IPA studies

Smith et al. (2009), whilst cautioning against checklist styles of quality assessments, utilise Yardley's (2000; 2008) work to evaluate quality in IPA studies. Qualitative work should be assessed according to criteria that are recognised as being appropriate for it (Bryman et al., 2008), rather than by more positivist standards such as generalisability, or through any process by which the assessment may become automatic or simplistic. This again echoes the epistemological stance. However, there have long been calls to argue for and justify the value and quality of qualitative work, in response to which Yardley (2008), Creswell and Miller (2000), Tracy (2010) and others have provided suitable mechanisms whereby such quality assurance can be shown, irrespective of the theoretical basis of the study in question.

Maybe it's because I'm an 'engineering' student, or because I have had to justify myself to some of the potential funders – it's so hard to convince people that 'just a few people' means anything at all. People are so fixated on the generalisability of research that it is a good question to ask. Instead of discussions around quality in qualitative work, however, I find myself talking about the fact that this is a hard to contact, possibly not very large group, and we're not getting helping them right, and that as nothing has been done with them so far, we need to start here so that we can start to support them and 'do further research' with them later. While that seems in some way to satisfy them (and is true of course), I'm not sure I've convinced many of them that IPA is so very much more than some sort of glorified journalism or story-telling exercise, when actually, it is pretty systematic. (Later addition) Mind you, I did win the funding.

Sensitivity to context is one such mechanism; this is demonstrable through the choice of IPA in this study (Yardley, 2008). As stated, I wanted to pay such close attention to the participants' own accounts and allow them the space and time to narrate their experiences. IPA's focus on idiography allows me to do this, so was applied from the earliest stage of the research (Smith et al., 2009). It is through the data, however, that sensitivity to context is most plainly manifested. The interview transcripts provided *"suitable and sufficiently rich material"* (Willig, 2017 p.12) for my interpretation of it to be substantiated within it. The findings chapters contain many verbatim extracts from the transcripts so that readers can connect with the participants' own voices and consider for themselves the interpretations that have emerged. Commitment and rigour are shown through the commitment to dedicating care and attention to each participant through the process of data generation and in turn to each section of individual data analysis and the commitment shown to the subject matter; rigour is concerned with the meticulous nature of the study. Here, the sample is fitting, the interviews generated much rich, useful data and the analysis was comprehensive (Smith et al., 2009). Verbatim extracts also demonstrate rigour as well as developing and supporting my own points of interpretation throughout the analysis.

Readers can trace the research process throughout this chapter and the following chapters (McCormack and Joseph, 2018), which shows transparency, and establishes further rigour (Tracy, 2010). This includes the ways in which the data came to be generated, how the sample of participants were identified and approached as well as the data analysis itself; the reader can determine pertinent points about what is important to each individual, where clarification of contextual meaning is evident in thick description (Creswell and Miller, 2000; Tracy, 2010). In addition, pertinent points about the themes (Smith et al., 2009) can also be determined, as these iterative processes have been detailed clearly in order to provide credibility (McCormack and Joseph, 2018). All participants have a voice, but not every theme discussed in the following chapters will have supporting extracts from each participant, although each has fair representation in the overall narrative. Tracy (2010 p.837) uses the term *"sincerity"* to further this discussion; good quality research should be transparent about all aspects of method and methodology, and about the reflexive process. The data here could, as Smith et al. (2009) suggest, be audited by another researcher. This was performed by a supervisor in the earlier stages of analysis, on one 'worked example'.

Yardley's final principle is impact and importance (Shinebourne, 2011). The current research meets this criterion, as this study has also created interest in wider political contexts, and I have spoken in various forums about it. Knowledge about CO exposure is generally lacking but is of vital significance to us all. As well as learning about the dangers of CO and how to protect themselves, readers can also appreciate the difficulties and lack of support available to those for whom the awareness raising messages are too late. Participants also have their voices heard and their marginalisation, in some cases, is highlighted (Larkin et al., 2006; Larkin et al., 2019). Further examination of this point has taken place in the introduction and is developed in the discussion.

## Evaluation of IPA: Criticisms and limitations

Sousa (2008 p.149) states that IPA has a somewhat perplexing theoretical basis. It presents the theoretical basis in *"two pages"*, merging different theoretical stances without clear explanation of how they align. In particular, phenomenology may convey different concepts to different readers, and IPA does not clarify this. Giorgi, an adherent of Heidegger, has further criticised IPA as not being truly phenomenological in its nature; for example, the inductive (or adductive) approach detailed by Smith et al. (2009) does not, according to Giorgi (2010; 2011), fit phenomenology, which instead is *"intuitive and descriptive"* (Giorgi, 2011 p.201). Van Manen (2017) also questions the phenomenological approach. For Giorgi (2011), this lack of fit is mainly due to the absence of the Husserlian phenomenological reduction and the bracketing of pre-understandings. Phenomenology, however, is not consistently applied by researchers and the term is a contested one (LeVasseur, 2003). In addition, Smith et al. (2009) have moved away from Husserlian bracketing towards recognition of more interpretative research approaches, where bracketing is neither feasible (Relles, 2015) nor sought, as awareness of preunderstandings can create wider meaning to be explored via the *"bandwidth"* of reflection (Smith et al., 2009 p.189). Smith (2010) also responded to Giorgi's criticisms himself, stating that IPA does indeed have a phenomenological and a hermeneutical basis, and that Giorgi's comments were based on his study of only a portion of the corpus of IPA work.

IPA has also been criticised, as have many qualitative studies, for small sample sizes and a lack of generalisability. There is a dearth of literature on CO exposure from the perspective of those who have endured it, as previously mentioned. The focus of this study is the participants who have been exposed to CO and have never before had their voices heard, and the study therefore is idiographic rather than nomothetic, in order to bring those unknown accounts into being and to the notice of healthcare professionals and policy makers. Todorova (2011) has also criticised IPA for this idiographic stance which centres on addressing the individual and their immediate context, rather than including any wider social context of that individual and from within which the individual's experience is produced. Smith et al. (2009) postulate that a growing corpus of idiographic work on such neglected areas may lead to the development of theoretical statements in those overlooked subjects, and Smith (2012) welcomes future developments for IPA which expand those concerns (Willig, 2017).

Language and its limitations have already been alluded to elsewhere; there is a preference for IPA researchers to desire participants to be articulate and persuasive in their accounts in order to generate the rich data required for analysis (Brocki and Weardon, 2006). IPA makes the assumption that words can communicate the experience effectively (Willig, 2013). The participants in this study expressed themselves eloquently and the data generation methods worked well with rich, detailed and in-depth data generated. This may not always be feasible, especially for participants who have undergone the trauma associated with CO exposure and may be living with the associated effects of that trauma and sequelae which affect aspects of their cognition. Therefore, this design may not have suited others who have experienced CO exposure.

Further to this, as discussed by Murray and Holmes (2014), there is the potential issue of researchers not paying much attention to those prosodic elements that could enrich the data; to whit, the use of Merleau-Ponty's (2002) philosophy regarding language and embodiment. Curstaidh, for example, often moderated her tone depending on her emotions; I especially noted that she would raise her voice for emphasis when discussing the blunders of her landlord which put herself and her son in extreme danger. She would rap on the table in time with her words to express her depth of feeling at times. Larkin et al. (2019) state that interest in such language functions can be drawn upon in analysis, while Eatough and Smith (2006 p.485) maintain that IPA takes a *"light constructionist stance"* in this regard. I found, that the first stage of listening (again) to the recording and reading and re-reading each transcript, giving careful consideration to all of these nuances in tone, pace and pitch, allowed for a vibrant picture of the interview and informed the next stage clearly. Similarly, as IPA is a combination of shared meaning-making between myself as researcher and the participants, my own facility to reflect and analyse on the participants' accounts is crucial (Brocki and Wearden, 2006).

Another issue with IPA which can be considered a limitation is the argument which states language itself constructs, and does not describe, reality. Words chosen to convey a particular experience will always fashion a certain portrayal of that experience (Willig, 2013) and any event can be relayed in many different ways depending on the context. The interview transcripts will therefore tell me about how the person discloses their experience rather than the *"experience itself"* (Willig 2013, p.67, emphasis in original), as acknowledged by Smith et al. (2009). Discussion of rehearsed and naïve accounts takes place in the following chapters; some participants were used to talking about certain aspects of their experience (although not in its entirety and not in anything like as much depth as they chose to share with me) as part of their work in raising awareness. This will also depend on the context of the discussion and extends into the analysis of the transcript and my own role as an interpreter, and emphasises the role of reflexivity.

# Chapter four:

# Methods in IPA

## Introduction

In this chapter I discuss the methods used in this study. Data generation, including use of the adapted Biographic Interpretive Narrative Method (BNIM), and important ethical issues that arise when conducting research into topics that are of emotional importance are explored. In addition, I also explain the revisions to the original plan for the methods, as the inductive approach I used led to adaptations in design and execution as the work developed. It concludes with discussion of points of negotiation and ownership of the research between myself and the participants in what became novel and appropriate methodological approaches. The participants again have a voice here and illuminate the inductive nature of the design.

## Data generation method

Garnham (2012) discusses the term data generation as appropriate for when data is created from researcher interactions with interview transcripts: *"data are not considered to be "out there" just waiting to be collected; rather, data are produced from their sources using qualitative research methods"* (p.2, author's punctuation). Interviewing has long been considered a standard method of qualitative data generation, almost irrespective of methodology, as it provides a forum for participants in which their experiences can be shared and freely explored (Wimpenny and Gass, 2000). This method of data generation is therefore most appropriate for the nature of the topic under discussion. In IPA, semi-structured, one-to-one interviews are the usual and preferred method (Smith et al., 2009; Willig, 2013), as they allow a rapport to develop between participant and researcher. As such, in an atmosphere of encouragement in a private setting, they are suitable for eliciting thoughts, feelings and detailed accounts from participants on what may well be a personal experience that is difficult to share (Smith et al., 2009; Lee and Renzetti, 1990). Interviews have a clear focus on one individual's personal experiences, meaning they are ideal for an IPA study with the emphasis on idiography (Smith, 2011).

Data generation was slightly divergent for some participants. Tisha and Ajay are a dyad of two people who underwent exposure together. Daisy's specific contribution was not analysed, as she had not been exposed to CO, but she did illuminate her husband Matt's experience of exposure to CO and added context and explanation for the events that subsequently occurred and were affected by this exposure. She also encouraged him to refine his meaning and present more depth on occasion, as can be seen in the findings chapter.

## Planning the interviews

As IPA data analysis requires rich, in-depth data indicative of deep engagement with each of the participants' lifeworlds (Smith et al., 2009), it tends to avoid the formality of a more structured approach as a means of data generation, since this may hamper the contextual nature of a narrative (Mason, 2007). Such questions may in fact cause the participant to become reticent and not articulate or express as much as they may wish, and may neutralise the spirit of the IPA, participant-focused interview. Interviews were therefore designed to gain access to the phenomenon of CO exposure and to give voice to people who have experienced it (Larkin et al., 2006). At the initial design stage of the study, I needed to be mindful of the aims of the endeavour in the light of the theoretical framework. These aims were capturing participants' subjective experiences as well as identifying through the analysis whether and how one experience differs from another (Plummer, 2001).

Smith et al. (2009) describe qualitative interviewing as *"a conversation with a purpose"* (p.57). Semi-structured interviewing allows for the importance of participants' own perceptions and understandings to surface (Lester, 1999). In order to facilitate a less formal atmosphere, I initially wrote and learned a comprehensive interview schedule, setting out the areas of interest in the form of open-ended questions, prompts and probes to be used if required or desired. I viewed the schedule as no more than a 'loose agenda' and was prepared for this to change during the actual interview itself, which should be led by the participant and their important points concerning their

CO exposure. This process enabled me to think about my research questions and design in an iterative manner; it allowed me to think about what would potentially be disclosed in the interview setting as well as how that information could relate to the whole study and theoretical framework. It also allowed me to reflect on the fact that I would be asking participants to divulge answers of a possibly sensitive, private or distressing nature, as well as consider how to signpost people to further support. I anticipated that I would explore unexpected issues which were relevant to the participant, and thus relevant to the research questions and analysis. Such unexpected avenues may deliver the most interesting and valuable information, as the participant is the experiential authority on their own experience (Smith et al., 2009).

## Biographic Narrative Interpretive Method (BNIM)

This method of biographical research allows for a surfacing of the variety of perspectives that people hold. More structured approaches can lead to dominant and *"official press-release"* perspectives (Wengraf, 2006 p.2), rather than allowing the participant to draw out their narratives of experience. This is something that is pertinent to this particular group of participants; the facilitation of voicing the more implicit perception was important in gaining their perspectives. This held particular resonance for those who had talked about their experiences to the media. This phenomenon, which I have termed rehearsed versus naïve accounts, is discussed in more detail later. Curstaidh, I knew, had not been hospitalised, but there were other focal points to her account, which it turned out were crucial to her experience and perspective of CO exposure. We had decided that we should have an unstructured 'chat' where I would just ask her to share her experiences regarding CO. I took

Curstaidh and BNIM:

Curstaidh was going to be a pilot; she had not suffered from acute CO exposure, and at the time, I did not realise that lower level CO would have an effect.

Excerpt from journal after meeting her:

The literature is all about acute exposure, from the perspective of the people who had treated them in hospital. Curstaidh's exposure is 'just' due to lower levels of CO over a long-ish period, and I think I've been thinking that they will probably all have had acute exposure? (I didn't think about the lower level stuff; I didn't even know there was any such thing as lower level, ongoing exposure before this. Wow.) **But** if this was her experience, and if *this* experience represents a gap in the literature (the utter dearth of information about CO exposure from the perspective of those who had suffered it), then she should have a chance to tell her story and be given that voice. Her experience is her experience; maybe I shouldn't have been 'expecting' anything else with the theoretical framework…

a minimal role in this, actively listening and asking for clarification about the points that she was making. Our discussion yielded a large amount of rich data. I had essentially posed a SQUIN – a Single Question aimed at Inducing Narrative (Wengraf, 2006), which formed the basis for the rest of the interviews. This question was, by the time of the next interview, which was with Bookie:

> *"Please can you talk about your experience with CO?*
>
> - *Start wherever you like*
> - *Take all the time you need*
> - *I'll just listen*
> - *Anything you choose to talk about is relevant; if it's important to you, then it's important to me and the research*
> - *I might take some notes if that's ok?"*

BNIM involves generating data over a series of interviews, starting with the SQUIN, allowing the participant to speak freely about whatever is important to them, with some facilitation but no direction from the researcher (Corbally and O'Neill, 2014). A second interview, taking place after careful listening/transcription, is focused wholly on the narrative using the transcript as a basis for further discussion and prompting, meaning the questions are individually tailored to that participant, and only elicited from the topics mentioned by the participant in the first meeting. The second meeting's questions were asked in the order of the transcript, further supporting the leading role of the participant in the process; there is precedent for this in IPA studies (Smith et al., 2009; Finlay, 2008). Since between one and three weeks passed between interviews one and two, it was considered that this was not enough time to envisage any meaningful differences in the sense-making experience of each participant (Eatough et al., 2008), therefore this was appropriate for the theoretical framework.

Speaking to participants twice led to increased rapport as well as the generation of enriched, highly detailed data, allowing participants to engage with the meaning-making process. Participants who are visited twice feel that they have a share in and are involved in the research project as more than just givers of information (Read, 2018).

I was clear that I was just using BNIM as a method of data generation and not analysis, and found that as such it lends itself well to the principles of IPA and its theoretical framework. Indeed, Smith et al. (2009) discuss returning to participants with data from a first meeting used as a prompt for discussion in the second; this ensures that participants have a definite role in shaping the data generation process (Smith, 1994). I still wanted to adhere to the idiographic, hermeneutic nature of IPA and its framework however, so the steps of analysis remained unchanged from those set out by Smith et al. (2009). Analysis of BNIM is co-created with other researchers (Wengraff, 2006; Corbally and O'Neill, 2014), whereas IPA depends on the hermeneutic approach of the interpretative essence of the findings (Smith, 2018).

## Alternative data generation methods used in IPA: Dyads

Out of a total of 11 participants, eight were interviewed individually, with the remainder forming dyads. Reliance on individual interviews in IPA is altering, with some IPA researchers utilising methods such as focus groups, for example Knight-Agarwal et al. (2014), Philips et al. (2016) and Palmer et al. (2010). This is despite some misgivings about the possibility of a truly phenomenological interaction between individual(s) and researcher in a group setting (Dowling, 2005). Smith and Eatough (2007) allude to the difficulty of following individual meaning-making in such settings, where the 'group' may be privileged over the 'individual'.

However, Smith and Eatough (2018), Smith (2011 and 2011b) and Todorova (2011) are among the authors calling for more innovative strategies to be used in IPA. The use of more inventive data generation has thus become more frequent.

Todorova (2011) discusses the resultant variance in epistemology when the focus is not entirely upon one participant sharing their own perspective on their particular lived experience (Larkin et al., 2006). It could be argued that there is a slight shift in the idiographic and thus the epistemological nature of the methodology if more than one voice is heard at a time. However, Smith (2011a p.56) envisages IPA work that explores the *"individual and experiential more in relation to the contextual"*, which is resonant here as CO exposure occurred in a family setting (Ajay and Tisha) and deeply affected family life (Matt and Daisy). I have also endeavoured to keep the idiographic focus at the core of all analyses (Todorova, 2011; Smith, 2011a).

Interviewing dyads as part of this research was interesting, but distinct from using focus groups as a source of data. The BNIM method of data generation would not have lent itself to a group setting, and a focus group may have consisted of up to eight people who had undergone a similar experience, in this case, CO exposure. Their symptoms, the contexts of their exposure and the aftermath of that exposure could have been divergent. The dyads of married couples, however, were already familiar with the other person and many of the nuances of each other's experience. Certainly, interviews of dyads enrich the data, as the experiences of both members of the couple can be analysed; this includes partner interactions which might not be apparent when interviewing individually. This interaction forms an additional layer of the *"part-whole dynamic"* (Tomkins and Eatough, 2010 p.245) or hermeneutic circle (Willig, 2017).

There are not many IPA studies which have used dyads for data generation: Boland et al. (2012), Banerjee and Basu (2016), McGregor et al. (2014) and Ummel and Achille (2016) explored dyadic relationships but interviewed participants who were part of a relational dyad (for example, romantic partnerships) individually. Wawrziczny et al. (2016) and Mavhandu-Mudzusi (2018) are among those studies that deal with the dyad of a partnership in a stable relationship, interviewing that couple together, looking for interactions and shared experiences. The authors explain that there are more levels of interpretation to be gained from such an interview, which includes two individual accounts and the experiences of each partner, and which also contains interpretation of the other's experience, and interactions with each other about each of those facets of experience. There are points of divergence and convergence. There is also the issue of the impact that CO exposure had on the relationship of the couple, as exposure undoubtedly did for the dyads in this study.

## Dyads in this study

Tisha and Ajay are a married couple who wanted to be interviewed together, after experiencing CO exposure together in their home. Matt, although exposed to CO when he was working alone, found that his home-life was affected by his long-term symptoms of exposure, including his ability to process and experience emotions, leading him to suggest that I might want to include his wife, Daisy, in our conversations. We three decided that I would talk to Matt first and then Daisy would join us, and this would happen for both interviews. Matt thought that Daisy would have a different perspective on their family life and how this was disrupted; for Matt, this was an important part of the account. Matt had suffered exposure and Daisy had not, so her account, although valuable in illuminating what happened to Matt as a consequence of his exposure, was not included in the analysis.

The dyad interviews offer a position in which the phenomenon of CO exposure can be understood even more completely, as dyads are a familiar and commonly encountered social context; they are a comprehensible unit in which an idiographic focus can be seen in conjunction with an analysis of a relational dyad (Larkin et al., 2019). The phenomenon of living with the aftermath of CO exposure is not only found in the accounts of an individual who has experienced CO exposure, but also within the accounts of those belonging to the lived world of that person, such as a spouse, partner or other family group. Tisha and Ajay had experienced the phenomenon together and as stated, wanted to participate in the research together. In Matt and Daisy's case, her lived world was irrevocably altered by his exposure to CO and the damage that caused to his health. This study therefore has a multi-perspectival facet in its design, which has meant that the research questions have been addressed more effectively (Larkin et al., 2019); for these people, sharing their

Problems with memory and cognition are well documented as effects of CO exposure. Matt was willing and perfectly able to give consent, and was eloquent about the effects on his memory, motor function and emotional health that CO exposure had had. He was also very informed and had given a great deal of thought to issues around CO exposure from lenses as diverse as housing, poverty, legislation around the Gas Safe Register, and the effect of CO exposure on different people with different metabolic rates. It was Daisy, however, who detailed an expressive and poignant account of how their family life had been adversely shaken by Matt's exposure.

accounts as part of a dyad captured interactions about both individual and collective experiences. I was able to examine these joint accounts through a lens for elucidating the broader meaning and consequences of CO exposure, in order to clarify its wider implications (Larkin et al., 2019), and to explore how CO exposure and living with the aftermath had impacted people's lives and relationships.

## **Sampling**

11 participants is a reasonably typical sample size for an IPA study (Smith et al., 2009; de Visser and Smith, 2007). Choosing a sample of participants in any qualitative methodology is clearly of paramount importance and, as already stated, a purposive sample (rather than one identified using probability methods) of participants who have been exposed to CO and are willing to contribute to the study was required. The sampling strategy relied heavily on, and had a strong association with, the theoretical framework of the study. Purposive, non-random sampling is consistent with the aims and objectives of qualitative research methodologies (Thomas, 2013), as the aim is never to measure attitudes or opinions but instead to explore the lived experiences of people who have undergone a specific event (O'Reilly and Parker, 2013). Rather than, therefore, saying something broader about a large population of people who have experienced CO exposure (Smith and Eatough, 2007), a sample such as this one will *" 'represent' a perspective, rather than a population"* (Smith et al. 2009, p.49, authors' punctuation). IPA studies are conducted with relatively small samples, as the main concern is to consider each case to the fullest extent, and not generate any theory to be generalised across the population of all who are exposed to CO (Pietkiewicz and Smith, 2014).

As de Visser and Smith (2007 p.352) state, participants' accounts do allude to stances and perceptions which they own *"experientially and cognitively"*. If one makes the assumption that IPA is essentially concerned with detailed accounts of individual experiences, then it can be seen that determined attention given to a smaller number of cases is appropriate, as supported by Smith et al. (2009).

Sampling reflected a challenge and a source of anxiety as it was difficult to ascertain the exact size of this population, and it was consequently problematic to make contact with potential participants. The purposive sampling strategy relied on networking and word of mouth, and I did not look to stratify the sample, or for any sort of cross-sectional representation in terms of common variables such as age, ethnicity or gender, or cultural or economic contexts, as I did not want to exclude any potential participants for this study, which is the first to seek the perspectives of those who have been exposed to CO. This is in keeping with an IPA study such as this, where the topic of interest has not been examined beforehand (Smith et al., 2009). I sought the help of some of the CO charities, whose directors kindly agreed to act as gatekeepers. Individuals who had been working with these charities were asked by the directors if they wished to read the information materials (appendix 15) and contact me directly. As I was cognisant of the issues around the supportive work of the charities and the fact that some of their service users may feel grateful or even indebted to them, I was clear that there was no direct involvement between myself and the charitable organisations. There was therefore a pragmatic element to the sampling strategy, as the boundaries of the potential sample were delineated by the paucity of the phenomenon (Smith et al., 2009); I was contacted on an ad-hoc basis by potential participants, and word of the study spread quite slowly.

As stated, the generous gatekeeping of charities provided some participants. This was augmented through the use of snowball sampling (Lincoln and Guba, 1985; Bolderston, 2012), as a participant would know of others in the same position and tell them about the study. Some participants heard about the research through my own networking and advocacy work around CO exposure, and contacted me about becoming participants: the participant pen portraits contain information about how each participant became known, or made themselves known, to me. People are, in fact, still contacting me through others who forward my details. Recognition that CO exposure is being given attention from the academic community seems to be especially important to this group. Sample size was eventually determined by the data that was generated from interviews (Boland et al., 2012).

## Homogeneity and inclusion and exclusion criteria

The group of participants is homogenous in the sense that they have been affected by CO and have the experience of being exposed, therefore inclusion and exclusion criteria were relatively straightforward. Inclusion criteria comprises those who are over 18 years of age, could conduct the interview in English, have the capacity to understand the research process and subsequently consent to it, and have experienced CO exposure. Since recalling a traumatic experience can be daunting, and the work of Mercer et al. (2012) would indicate that a time lapse between the experience and the recounting could ameliorate this issue, I considered the idea of stating that a certain time period should have elapsed. This would mean that potential participants would have had time to reflect on the exposure and any sequelae, and that they were less likely to be still coping with any shock from an exposure incident (Boland et al., 2012). I appreciate, however, that trauma is a subjective experience and any such timeframe would therefore always be somewhat arbitrarily imposed by me, so this idea was not pursued. Again, as no lived experience research with anyone affected by CO has been undertaken, the aim of this study was to gather accounts of exposure from the perspectives of those who had been exposed, under any circumstances.

The only exclusion criteria was that CO exposure had to have been caused by unintentional means. It was thought that anyone who had used CO in order to attempt suicide, would know and possibly understand that CO had caused symptoms that may have lingered, or developed after their exposure. This particular group of people may also have existing health-related problems that would be difficult to acknowledge in the analysis.

IPA research habitually explores areas of shared perspectives on a single phenomenon (Larkin et al., 2019). While all participants had been exposed to CO, there was a division between groups one and two. My sample could therefore be perceived as not being truly homogeneous, which could be identified as a limitation (Smith et al., 2009). Some suffered a shorter-term exposure; in some cases this would have been exposure to CO over a relatively short period (for example, over several hours or overnight), while others suffered exposure over a longer period. This could entail months or even years – Be, for instance, was exposed for over six years and Sarah and Kate for three years. Wright (2002) would offer the classification that there were people exposed acutely and people exposed chronically here; but this is acknowledged as a rather loose definition for this group, because as discussed elsewhere, the exact levels of exposure have not always been recorded. Moreover, such readings do not ever give a true picture of the extent of exposure (Bleecker, 2015).

In IPA studies, groups are usually defined as homogenous according to important variables (Pietkiewicz and Smith, 2014), and a *"probable shared perspective"* (Larkin et al. 2019 p.182). While in a broader sense this is the case for the current sample, the dichotomy between those groups could illustrate the point that they do not share quite the same experience. As previously stated, however, since so little was known about the experiences of anyone who has been exposed to CO under any circumstances from the perspective of the person affected, it was decided to look across the scope of exposure.

## Ethical considerations

The interviews took place after ethical approval had been sought and granted from Liverpool John Moores University Research Ethics Committee (appendix 16). All participants were fully aware of what the study entailed (Oliver, 2010) and there was careful negotiation to ensure clarity, especially for the dyads (Larkin et al., 2019) who would be sharing information with each other, as well as with me. Naturally, I did not wish to make unwarranted judgments about participants' proficiency, or label them unnecessarily as vulnerable participants. It was, however, necessary to establish that individuals had a good enough understanding to consent to participating in the study, as neurological conditions that are the sequelae of CO exposure may affect cognition (Ho et al., 2012; Hopkins et al. 2006). Therefore consideration was needed around establishing whether participants had the ability to proffer informed consent. These particular participants could be said to be inhabiting *"risky spaces"* (Farrell, 2007 p.3). As stated, an information form was devised which detailed the purposes and data generation methods of the research as well as processes for anonymity, confidentiality and destination of the data and analysis (appendix 15). This and any conversations with the participants revealed my own position in a further attempt to allow for openness between the participant and myself (Relles, 2015). The consent form (appendix 17) was discussed with participants and signed by us both at the first interview. As necessary, full explanations were given to participants to make certain that they comprehended the process.

## Reliving the experience

It is to be expected and appreciated that the nature of such research may be perceived as distressing to varying degrees whilst participants narrate negative experiences. It was difficult to predict whether and to what extent simply talking about such sensitive issues could constitute harm for each individual (Oliver, 2010; Walsh, 2007). It is considered good practice in IPA to further discuss the issue of consent during the interview itself in, for example, an instance where an unforeseen sensitive issue that may cause distress emerges unexpectedly (Smith et al., 2009). This can be seen throughout the transcripts. Participants showed signs of distress and tearfulness on occasion; I would ask them if they were all right, and reiterate the suggestion that we take breaks for as long as they felt necessary, or discontinue the interview. Occasional breaks were taken, mainly at the participants' request, sometimes by my suggestion or encouragement, but all interviews continued and were completed. I would also start the interview by reminding participants that they could withdraw at any point, and I would state at the beginning of the second interview that they could omit answering any of questions as they chose. As it happened, most participants were glad to be talking and the flow of the interviews remained largely uninterrupted. For instance, Be stated that the experience, even though upsetting at times, was *"healing"* (lines 2750 and 4596) and that she was more than

Excerpt (after Ajay and Tisha 1st interview): As time goes by and I talk to more people, I realise that the function for at least some is not just to 'kindly' take part in my research, but to release something very important and reach some sort of catharsis? Not for the first time, I'm feeling the responsibility of doing a 'good job' here – not just researching, but wishing I could be somehow *helping* them. The best I can do in this role is to listen and support them – some things they have never said to anyone before.

happy to carry on talking about her experience of CO exposure; in fact, she found the experience or talking about it to be helpful. I signposted some respondents to the charity from which some of the other participants had been recruited. Additionally, I had sought out local organisations which offer counselling or other support, and passed this information on to participants.

## Relational ethics

Relational ethics state that all human relationships are influenced by the power dynamics inherent within those relationships (Austin 2012). Closely linked to both the methodology and theoretical framework of this study, relational ethics recognise that people who are marginalised in some way, in this context by their exposure to CO, can be considerably disadvantaged. For some participants, this has meant fewer opportunities to have their voices heard. Be, Lizzie and Sarah come to mind at this juncture, as not only were they not heard, their concerns were completely dismissed. My approach, therefore, sought to address issues of power and vulnerability (Austin et al., 2009). Relational ethics are in some ways a response to biomedical ethics committees' focus on the notion of the autonomous individual. Although respect for the autonomy of the individual (for example, Gillon, 1994) is rightly valued, and linked to concepts of rights and freedoms, Austin (2012) considers that this does not give us a true image of the connectedness and interdependence of the innately social nature of human lives and experiences. For example, although she was respected and she stated that she felt heard and could express and relate her experience of CO exposure in the way she chose in the research process, the notion of 'autonomy' is not reflected in Be's lived experience. As such, an *"overemphasis on autonomy can create a false picture of a*

Excerpt from diary after 1st meeting with Sarah:

Don't know why, but I wasn't really expecting Sarah to become upset (tearful), or at least not so early on in the process. It was maybe a combination of her being 'allowed' to talk about 'all of it' with someone who understands CO issues, at least from my POV (she'd asked me to stop her if she was 'talking about irrelevant stuff' and I reiterated that if it was important to her, it was important to the research). Then there's the associated relief of just telling someone, finally, the totality of this awful thing that has just fragmented and stolen your life. She had come across in our communications before that as someone who was just very articulate, passionate and really, really angry and frustrated about the whole thing. I think her reaction shows how important it is to have the space to talk about it. It completely highlights the need for support for people who have experienced it. I've come away feeling massive amounts of sympathy for her, not least because of the things we have in common, and that she's had/is having such an awful time.

*person's everyday situation"* (ibid p.3). Be was not listened to or respected by many, including healthcare professionals, culminating in her being *"accused"* (line 754) of having the mental health condition Munchausen's Syndrome by Proxy (MSBP) (now known in the UK as Fabricated or Induced Illness (FII) (NHS, 2016)). Relational ethics are therefore about interdependency, emotions and our *"unique situation"*, and encourages sensitivity to the whole context (Austin, 2012 p.4).

Relational ethics recognise that current ethical guidelines may not be sufficient (Austin, 2012), and call for researchers to be ethical in their approach to others. By this, Austin (ibid) is talking about mutual respect, attention to the interdependent environment and attention to uncertainty and vulnerability. I endeavoured to uphold these ideals by engaging in careful discussion with participants, paying careful attention to the situation, and being sensitive to the whole of that context. Dialogue was also modified to be more inclusive and ownership was promoted (by omitting the use of the word 'interview' and encouraging participants to choose their own names; see below). Certainly, visiting twice also facilitated this relational ethical aspect. The natural increase in rapport that we achieved was also advantageous.

## Ethical considerations: dyads

Ethical considerations for the dyads drew attention to the importance of the dynamic nature of good ethical practice in IPA studies. These interviews were conducted in the presence of the dyad, so that it was clear that anything that was said would be known by the other. I had concerns that this may have had an effect on the particular relationship between two individuals, as something hitherto undisclosed between them could have had a negative impact. Again, negotiation to ensure clarity about the research and what is entailed during planning and data generation, as well as what will happen during analysis and dissemination, is key here (Larkin et al., 2019). Continued from email and telephone discussions, and bearing in mind that they already had the information sheet, at our first meeting I therefore reiterated the nature of the discussions that we were going to have; that is, I would listen to them talk in the first meeting and then construct some questions and prompts from that discussion for the second. During the second visit, I envisaged that I might have different questions for each member of the dyad, but that I would ask all questions in the order that they came up, as I did in the individual interviews and thus following the order of their account in the first interview. I suggested to them that if they had something to add to the other person's question from their own perspective, that I would welcome that, as long as it was acceptable to the other person that this might happen.

## Gatekeepers

Gatekeepers (those who ran the charitable organisations) were given a similar information sheet and consent form to the participants (appendices 18 and 19). This asked whether they understood the nature of the research and stated that their role was to advertise the research to the people for whom they advocate. They were also made aware that I would potentially be signposting people back to them if participants became distressed during the narration of their account and wished for this to happen.

The role of gatekeeper was key in this context (Farrell, 2007). The issue is so unknown that the sample that I could connect with, even with internet access, would have been small and difficult to reach, so rapport with these gatekeepers therefore enabled me to access participants (Smith et al., 2009). Gatekeeping of participants, however, can be potentially challenging and affect the research in ways that may never be known to the researcher. For example, gatekeepers may limit or even deny access to certain service users (Lee, 2005), or make judgements about who they think would be a useful person to take part in the research.

## Interview location

Pietkiewicz and Smith (2014 p.7) allude to *"naturalistic"* settings for qualitative research. They include homes, schools and hospitals in this definition. The aim is to avoid inconvenience for the participants and to try to foster a sense that they have some ownership of the process, in order to reinforce the issue of their voices being heard. Therefore, participants in the current study were given a choice of when and where to have the interviews (Bolderston, 2012; Mavhandu-Mudzusi, 2018). The idea of giving ownership also fits with the theoretical framework (Bell, 2011; Varpio et al. 2017) and hermeneutic approach (Willig, 2017); in this instance, interview location was entirely left to the participants.

Curstaidh and Vivienne elected to have their interviews at their place of work, whereas everyone else was visited in their homes, at various times of the day or evening that were convenient to them. Again, this speaks of their ownership of the process; participants were respected and could, to some extent, relax (Mavhandu-Mudzusi, 2018). I noted that Curstaidh and Vivienne sound like they are 'at work' in some of the language they use in their accounts, for example the use of phrases like 'going forward', and generally talking about work, perhaps more than they would have at home. It is difficult to say whether being at work had any effect on their narrative (Richards and Emslie, 2000), but it is interesting to note that these phrases and modes of speech were present in light of the earlier discussion in the previous chapter about language in IPA. Van Waldron and Krone (1991) discuss the difficulty of allowing the expression of emotion in the workplace as a contraindication to the usual rules of workplace behaviour. Awareness of the influence of contextual details around being in the workplace is important in this process (Richards and Emslie, 2000).

In order to ensure that I remained safe whilst going to see participants in their homes, I followed Liverpool John Moores University lone worker policy which reflects common sense ideas about informing another person of one's whereabouts and contacting them when the interview was concluded. I recorded a risk assessment (appendix 20) as an example of good practice in this area.

## Points to note about this study: Rehearsed and naïve accounts

As detailed in tables three and four (appendices 12 and 13), some participants had related their accounts before, as they want to raise awareness about the dangers of CO. This can be seen to operate on something of a spectrum. At one end, for example, Vivienne generously gives of his time as he wants people to be better informed about the dangers of CO. He has given many interviews to the media and works exceptionally hard in this area. His account was therefore longer, and smoothly told in a chronological order, as his re-telling of the account for various media had allowed him to develop a different order of familiarity with its content (Rubin and Rubin, 2005). These differences are at least somewhat to be expected. Issues around multiple retellings of subjectively remembered traumatic events can emphasise different personal interpretations and viewpoints within diverse experiences (Hall, 2011).

This is not to say that naïve accounts were not smoothly told; but there was a difference between, for example, Vivienne and Showgirl's accounts in terms of flow, especially in terms of chronological ordering. Despite these differences, however, all participants felt the need to be heard in this research context. Media interviews, from what was said, could be focused in a particular way. For example, Tisha was asked who she *"blamed"* (line 591) for what she had been through, rather than being asked to talk about her experience in terms of whatever she felt to be important about it. Participants continue to feel that any way to transmit the message of how dangerous CO can be and how easy it is to suffer exposure is a worthy vehicle, and almost universally they felt that there should have been academic research on the topic before now. Whether participants had felt that they had had any sort of an outlet for their experience or not before talking to me, they still recognised that healthcare professionals and the public remain largely uninformed about key issues.

If they have had media contact, especially, some of the participants are used to talking about how CO had affected them and what happened when they got exposed. Could this actually have been quite significant to their accounts? Could there have been an effect on what was said due to the fact that it had been said many times before? There may have been, even if only in the delivery. Giving people the freedom to talk about what was important to them meant that some stuck more to a timeline than others. Showgirl, for instance, did not always give her account in this linear way. There is a marked difference between her account and Vivienne's for example. This could certainly be multi-factorial; personalities, backgrounds, etc. – yet it is interesting to think about what could have happened *differently* with participants who had never related the events before, if they had been talking to the press or anyone else about what happened; the main difference was in my role as interviewer.

## Points to consider: member checking

Member checking forms part of the range of tools used for quality assurance in qualitative research and can clarify miscommunication between researcher and participant (Carslon 2010). I have included an explanation of it here because it was suggested to me that interviewing participants twice was a form of member checking, where the researcher returns to the participant and checks that what was recorded at the first interview and the resulting transcript was what the participant actually wanted to convey; that their own experience and meanings are recognisable (Varpio et al. 2017). Member checking did not occur in this study – although, as stated, the second interview did involve the participant giving more detail and clarification about matters divulged in the first interview, there was no attempt to return after analysis as has occurred in other qualitative and IPA studies (for example, Bricker-Katz et al. 2013). This second point of member checking allows participants to validate researcher interpretations of data (Varpio et al., 2017). IPA, while phenomenological in examining the subjective lived experience of the participant who, in this instance, has had CO exposure, is also openly interpretative. My interpretation of what was said leads to emergent, sub- and superordinate themes and the development of arguments in the analysis and discussion of the data; member checking in the sense that it is used in other studies is therefore not entirely congruent with the theoretical framework used here.

## Novel methodological approaches: Interview – alternative terms

Although the interviews are referred to as such throughout this thesis, I did not use the word ‘interview’ during the process of advertising the research and then contacting and speaking to participants, or during our encounters. I used words such as ‘meeting’ and ‘talk’ instead. The word ‘interview’ is often perceived to be a ‘formal’ meeting in public perception, and I feel that it has connotations that could lead to stressful reactions. It can be seen as a term with different meanings; certainly, job interviews are not without their tensions. As discussed, some had already undertaken numerous interviews with journalists through several media formats because of their experience with CO exposure, and this was not universally relished by all participants. Participants may well also have had the doubtless difficult experience of being interviewed by the police (Bookie was interviewed; Vivienne was actually arrested). Avoiding the word with its difficult or negative connotations was therefore appropriate for this study, with its emphasis on relational ethics and power dynamics.

## Novel methodological approaches: Choosing of pseudonyms

All participants in this study have pseudonyms. Another form of ‘ownership’ that has been used in research with children and young people (Bell, 2011) that I tried to foster throughout the process was asking people to choose their own pseudonyms. Some asked me to choose names for them, and some picked everyday names very quickly, with two people requesting a particular spelling. This turned out to be an interesting exercise, perhaps especially with the ones who took slightly longer to choose. Bookie chose his name from a previous occupation, presumably from a time when he was happy in his work and his life, in the period before he was exposed to CO. Vivienne chose his as a way of honouring his beloved partner, who sadly lost her life; similarly, Matt’s choice honours a dead colleague of whom he was fond. Showgirl chose her name from her favourite pastime; perhaps most thoughtful, however, was ‘Be the change you want to see in the world’ (referred to throughout as Be), as a reminder of that participant’s commitment to raising awareness of the general public’s vulnerability to CO exposure.

# Chapter five: Data analysis

# Introduction

The procedure for data analysis using IPA suggested by Smith et al. (2009) was largely followed, with individual annotation followed by the production of emergent and then subthemes for each transcript before looking at the participants within their groups and then across both groups. This ultimately led to the emergence of the final superordinate themes, and this chapter charts my reflexive interaction with the data that led to those themes and the analysis (Varpio et al. 2017). Each process of interaction with the data allowed for more engagement with it, and each engagement was a step towards producing a richer, more interpretative analysis (Eatough and Smith, 2006). In keeping with IPA, an interpretative summary was also produced for each case (Eatough et al., 2008). Discussion of data analysis arising from the dyads of Tisha and Ajay, Matt and Daisy, as well as the advice that was used to undertake that section of the analysis, forms the concluding section of this chapter. Again, the participants' voices are used to inform the processes used.

Some of the transcripts are really too long to look like I can cope with them, and working out how to keep track of everything has become its own iterative/hermeneutic process. Happy that it's at least organised now; and happy that I've analysed Curstaidh's and it feels like that's raised confidence about interpretation. My first attempts did feel cautiously descriptive; going back again (hermeneutic), 'dwelling with the data' and allowing the themes to emerge did allow for more, deeper interpretation.

Dyads – choices made now. Will use the info from the focus group papers to inform, as this is slightly more directive about analysis than what I've found (so far) in dyad interview papers and can be adapted. Daisy's contribution has proved to be a quandary – it was wonderfully illuminating of what Matt himself, they as a married couple, and the whole family went through because of Matt's CO exposure, BUT I'm looking at own experience of exposure, so it now seems a bit discordant? Certainly an idea for further research though.

# Hermeneutic analysis

The aim of analysis, and indeed of the thesis, is to understand participants' subjective processes and meaning making of the experience as well as its sequelae through phenomenological interpretation (Murray and Holmes, 2014). Analysis has been discussed as an iterative and inductive cycle (Smith, 2007) or hermeneutic circle utilising the researcher's questioning approach (Smith et al., 2009) and with a focus on the relationships between the part-whole moving dynamically (Tomkins and Eatough, 2010; Willig, 2017). In order to achieve this, strategies such as a line-by-line analysis of the data, leading to emergent patterns of convergence and divergence within one set of data and then across other sets of data are employed. It may follow then that a structure, frame or Gestalt may be developed which details the relationship between themes and which moves towards a more interpretative rather than descriptive account. Any reader of the analysis needs to be able to follow the workings and interpretations made from the transcript to emergent themes, subthemes, and finally the superordinate themes which present the experience of the participants to readers. This organisation can be seen at the start of the process of analysing the data in table six, which shows a portion of Curstaidh's interview (appendix 21), with the descriptive, linguistic and conceptual comments. Table seven (appendix 22) shows the clustering of emergent themes into subthemes, again using Curstaidh's interview as an example, for continuity. The final stage of this process is to ascertain the superordinate themes that fit across participants' accounts. Table eight (appendix 23) shows how the emergent themes and then the subthemes were clustered and thus developed into superordinate themes, and table nine (appendix 24) shows a connection between each participant and each superordinate theme.

A full narrative may then be produced, containing a detailed commentary on extracts from the data, which allows the reader to follow the interpretation, and also may include reflection on the researcher's own perceptions, conceptions and processes (Smith, 2007). This narrative forms the following findings chapters. Smith et al. (2009) give a detailed account of the stages of the IPA research process in which the data has been generated through interviews. The authors stress that there is no clear and absolute way of conducting IPA research; although they proffer a step-by-step guide, there are IPA studies whose authors have *"been characterized by a healthy flexibility"* with regard to analysis (Smith et al., 2009, p.79). The authors therefore encourage researchers not to think of their step-by-step guide as a *"recipe"* (Smith et al., 2009, p.81) but as a means of connecting with the data.

In the interests of gaining confidence, it is recommended that novice IPA researchers such as myself follow the guidance offered in Smith et al. (2009)'s textbook. This I did; I considered, like Gee (2011) that the guidance served as instructional and also as a road-map, allowing for iterative charting of my progress with my analysis. After writing a reflexive account of the interview, I listened to each recording again, and after transcribing, re-read whilst listening. Smith et al. (2009) suggest making notes of thoughts that occur as this stage progresses; I found this to be helpful in *"reducing the level of the 'noise'"* (p.82, authors' punctuation) of ideas, relationships, and potential associations formed from the listening/reading. In the first instance, reading and re-reading enabled me to immerse myself in the data and ensured that the participant became the focus of the analysis. As Smith et al. (2009) state, the usual habits of quickly reading and processing information can be slowed in this way, so that the process of entering the participant's world through active engagement with the data can begin.

I then continued with the initial noting (Smith et al. 2009). As detailed below, I analysed the transcripts largely in the order that I interviewed the participants, with some exceptions. Smith et al. (2009) suggest that the first analysis may seem the most daunting; fortuitously, Curstaidh's, which I analysed first, was the shortest interview.

I analysed the data from the dyads in a slightly different manner. Although individual analysis was performed on the transcripts of Tisha and Ajay, and Matt and Daisy in terms of annotation and emergent themes, I also looked at them as dyads (see below) and therefore analysed these pairings separately before considering them in the context of the wider group of participants who had experienced CO exposure, since another layer of analysis was present. This process serves to integrate the experiences of the group by exploring the disparity and convergence between them.

## Transcription

The interviews were recorded and then transcribed verbatim, and lines were numbered. The first and second interviews were numbered continuously, as interviews one and two for each participant were treated as one dataset or transcript and analysed together (Eatough et al., 2008). The origin of direct quotes in the findings and discussion chapters can be seen in the pen portraits, (appendices 1-

12) as the number of lines in each interview are recorded there. This was also the case for those interviews where there was more than one participant present. While transcription was an onerous process, and one that can sometimes be undertaken by external transcribers, I did feel an immediate engagement with the data and the participants by doing the transcription myself. At times, it was tempting to 'start' the next steps of analysis while still engaged with this stage, as it seemed that so many ideas occurred to me that I could just circumvent some of the suggested steps and surge ahead. My IPA novice position, however, counselled more caution, and I committed to thoroughness in the process.

## Reading, emergent comments and emergent themes

The next phase involved *"semantic content and language use on a very exploratory level"* (Smith et al., 2009, p.83), and was the most time-consuming stage of the analytical process, with the aim of producing a set of exhaustive notes on the data. Appendix 21 (table six) shows how the exploratory commenting was conducted by examining the language used by Curstaidh, the situation from which she is relating these concerns, and identifying abstract concepts in order to form a connection with Curstaidh's lifeworld (Eatough et al., 2008; Smith et al., 2009). This was done by identifying and formulating descriptive comments (the substance of what was said), linguistic comments (ascertaining the specific use of language) and conceptual comments (engaging at a more interpretative, questioning and conceptual level) (Smith et al., 2009). The comments were recorded on the right side of the page using the 'comments' function in Office Word. This became quite dense at times, as so much data was generated in this way.

This resultant large data set then shapes the development of emergent themes, which were recorded in text boxes on the left-hand side of each page. At this juncture, I realised how much rich data could be elicited in this way. Curstaidh had been exposed to lower concentrations of CO over the course of several months, and I had come away from the interview feeling that she had resolved any issues over her experience and 'moved on', and that while she acknowledged that the exposure to CO could have resulted in far worse consequences, she was now, at the point of interview, relatively circumspect about the events surrounding her exposure. I wondered, as I left that interview, how much of Curstaidh's account would add to the development of eventual superordinate themes. This thought was allayed by engaging with the analytic process, which I found to be, as described by Gee (2011 p.11) *"alchemical"*, in that listening, reading and noting allowed me to begin exploring Curstaidh's words using the hermeneutic, questioning approach, looking at backgrounds as foregrounds, and enabling me to move beyond the descriptions of the first set of comments into the more interpretative linguistic and conceptual observations. This involved working closely with my notes on the transcript, rather than just the transcript itself, so that the emergent themes I recorded in a left-hand text box on the transcript reflected the words of the participant as well as my own interpretation; the themes thus reflect an understanding and interpretation of the participant's lived experience.

## Use of metaphors and analogies

Many of the participants used rich language to convey emotions about their experiences. Imagining or discussing something as something else results in detailed and multi-faceted communication; a more vivid level of understanding of what is being conveyed can occur, and new meanings can be presented (Shinebourne and Smith, 2010). Using metaphors can help people address and access experiences that are painful and can help them symbolise their experience in emotional terms that may have previously been unexplored or even unacknowledged (Lyddon et al., 2001), as a way of meaning-making (Shinebourne and Smith, 2010). Focusing on the role of feelings was important, as this allowed access into what the experience was like for each person (Eatough and Smith, 2008). For instance Be became distressed as she recalled her experience with some healthcare professionals. She said that they treated her as though she were *"a piece of <u>meat</u>"* (line 827). This forceful metaphorical language transmits, succinctly, the image of a person being treated not as an individual with consciousness, rights and autonomy, but as something far removed from that. It speaks of a lack of consent; even, a lack of consideration that consent *should* be sought; a piece of meat is not worthy of such agency as it is an object and is therefore perceived as being unable to feel pain and suffering; it is an insignificant, petty, dead thing. She felt dehumanised and humiliated by the healthcare professionals' uncaring attitude, and she conveyed that feeling extremely effectively through the use of her language. Again, as Gee (2011) found, I wondered whether I would have been so attentive to this comment of Be's had I not performed the linguistic analysis stage on her transcript.

## Subthemes

The next stage involved looking at how the emergent themes fitted together. In order to organise the emergent themes, I wrote them on slips of paper and began to arrange them into groups that shared commonalities. This physical act enabled ease of movement in and out of nascent groups and again helped me to move close to the data and then take a 'bird's eye', more abstract view, engaging the double hermeneutic. This again seemed an initially overwhelming and extremely complex task, and also, as I had moved away from what Curstaidh had said to what I had interpreted, it was at times uncomfortable (Smith et al., 2009). I was anxious about wanting to capture all of the meaningful elements of the transcripts and thus remain true to the participants' accounts, and I also had initially focused on the less abstract, more concrete components that remained closer to the data and further from my interpretation (for example, see appendix 22), and therefore had a great number (Smith, 2011).

Some emergent themes in the left columns 'merged' when developing subthemes and then superordinate themes; similarities in themes occurred between individual participants' transcripts but these similarities had been worded differently due to the idiographic nature of the whole analysis. Some were numerous and clearly shared much commonality across cases straight away, e.g. 'general ignorance' and 'levels of ignorance' and 'everybody seems to be in the dark'. This latter became a superordinate theme; it started out as an abstraction from Curstaidh's transcript.

This situation was alleviated, again, by following the advice of Smith et al. (2009), who state that the stages of analysis involve moving away from the participant to include more of the researcher's perspectives, which can illicit feelings of discomfort for novice researchers. They then specify several possible options for achieving this stage of the process, such as through the means of abstraction; that is, identifying patterns between emergent themes and developing themes from a group of common emergent themes. Another option that can be utilised is subsumption, in which an emergent theme itself becomes a subtheme by joining a series of related themes. Some of the phrases used by participants eventually ended up as emergent or subthemes, such as Bookie's *"no such thing as justice"* (line 453). Contextualisation, that is, the framing of cultural, temporal and narrative themes may also be useful. While considering how often a theme occurs may seem somewhat counter-intuitive in a qualitative setting, numeration, or attending to the frequency or repetition of the appearance of emergent themes, can also be of interest to the researcher. Repetition of themes may indicate their relative significance and relevance to the participant (Smith et al., 2009), particularly when, as in this case, the interviews were largely unstructured and each participant was free to talk about what was important to him or her, in the order in which it occurred to them to discuss it. Finally, examining the emergent themes for their specific function in the transcript can also be illuminating and reveal how the participant presents him or herself during the interview, a technique which Smith et al. (2009) acknowledge as being related to discourse and narrative analysis, but which in this context invokes the experiential. As an example, and as mentioned in her group's findings chapter, Sarah wanted me to know early on that she had thought that CO could not be a problem for her; she was a conscientious individual with knowledge who had a gas safety check and an annual service carried out on her boiler.

As recommended, I endeavoured to focus on the emerging ideas from each participant's transcript in turn, without recourse to previous already completed cases. This approach is concomitant with the idiographic nature of IPA, since allowing new themes to emerge in each case in turn attends to the individual, subjective experience of each participant's account. In order to do this, I left a break of several days between finishing one analysis and starting the next.

## Superordinate themes

To conclude the analysis, establishing patterns across cases is necessary. Themes may be represented in an individual case but may also signify higher order concepts that are shared across participants. In this research, as stated, instances of CO exposure were analysed across cases, using the same techniques. Convergence and divergence between them was also then able to be considered.

Again, I engaged with the hermeneutic circle several times throughout this process. For instance, identifying emergent themes means that the narrative flow of the interview was necessarily fragmented; the whole is not examined in its entirety at that time, but becomes a set of parts. Looking at the transcript of Curstaidh's interview, which was the first to be examined thoroughly, when one particularly meaningful element was noticed, a more detailed examination of that element was undertaken, so that the slow, step-by-step process from the particular (for example, a phrase that Curstaidh used) to the more universal (that is, the whole interview) can be observed (Smith et al., 2009). All of those elements from each case then came together at the end of the analysis. Constant reference was made to the earlier stage of individual analysis in which key comments were recorded, so as to ensure that the emergent theme and subtheme heading remained true to the original sense of the each participant's words. I wanted to be able to use, as part of my hermeneutic interpretation, the most poignant or fitting words from the participants; in a larger data set, this ensured that I would be able to follow the threads back to the 'right' place.

The names of the superordinate themes changed as analysis progressed, which also reflects the interpretative and iterative nature of the process. All participants talked about power and justice in some form; but other issues, although they didn't necessarily apply to many participants, were compelling and warranted inclusion. This issue of what to include and what to overlook was for me, like it was Wagstaff et al. (2014), indicative of a tension between the idiographic focus on each participant and the development of superordinate themes. Using the analogy of the increasing-decreasing action of an accordion to discuss the iterative development of themes, Wagstaff et al. (2014 p.7) state that the act of reflexivity and reflection on the research process is *"one of the processes whereby a novice researcher stamps their identity upon a study".*

Writing up, however, illuminated the importance of some subthemes over others, and played a substantial role in the interpretation itself (Smith et al., 2009). In addition, creating a structure to the organisation and development of themes helped. For example, at one point I designed a table, that although was too big for inclusion in the final thesis, incorporated the contributions of each participant to each sub- and superordinate theme. Truncated versions of this table are now at the beginning of each of the findings chapters (chapters six and seven).

Trauma and power were initially considered as one concept in 'trauma, power and negative changes', before realising that they would need separate treatment in order to display the depth contained therein. Initially, this theme had been tentatively and pragmatically labelled 'negative outcomes'. I wanted to elucidate some of what constituted and added to those 'negative outcomes', so additional parameters were added, for instance around the subject of court cases and the concept of justice, and how participants felt that they had (or did not have) any power or autonomy in those situations. I then realised that they were 'changes' rather than 'outcomes' as the interviews were at a specific time point and the word 'outcomes' indicated a fixed point that could not alter; they were only, therefore, 'outcomes' at the time of the interview and as such, not representative of the participants' experiences. The eventual superordinate themes ultimately further separated and became 'traumatic experience' and 'power, justice and judgement'.

Investigating issues of power that the participants shared with me became an intriguing endeavour. I determined that viewing the experiences connected with power through a lens of whether the particular aspect I was exploring was an extrinsic, imposed element – such as the discussions about gender in healthcare – or, conversely, was not, allowed a divergent perspective to emerge. Thinking about what was intrinsic, that is, the meaning that the participants saw as coming from within, led to 'identity and connectedness' as a superordinate theme.

Finally, the emergent theme ‘disparate systems’ was relocated from its original superordinate theme of ‘power, justice and judgement’. ‘Disparate systems’ was discerned initially as being concerned with issues of power so had been placed there; other people and organisations who had the power and opportunity to help did not or could not do so. I decided to move this theme to ‘everybody seems to be in the dark’, as it is primarily about the lack of coordination that exists around tackling issues around CO, which relates to the fact that many people are largely ignorant about these issues, especially in terms of CO exposure that was not recognised as being such for a longer period of time. It was the ignorance about CO, both before and after the discovery of its presence, that was the prevailing issue. These points demonstrate that the analytic process is iterative and multi-directional, with a constant shift between the different analytical stages that is only *“fixed”* by the act of writing up (Smith et al., 2009 p.81), where writing up itself forms part of the analysis and where resonance and disparity among participants was noted (Tomkins and Eatough, 2010; Smith, 2011).

## Analysis of dyads

Larkin et al. (2019 p. 190) recommend that researchers working on those studies which have used something other than the traditional units of analysis, such as the relational dyads used in this research, begin analysis with the individual cases and then *”move outwards”*. In this research, Ajay, Tisha and Matt were acutely ill to the point of collapse from the CO. After individual analysis of Tisha’s account, as part of the whole transcript, I next looked at Ajay’s, and then revisited the transcript to explore their interactions. This was repeated for Matt; Daisy’s account was her experience of Matt being exposed, so although all initial comments of her account were treated in the same way as Matt’s, emergent themes that were solely hers were not included, as this did not fit with the original aims of the research. A narrative was developed concerning the inter-relatedness of these experiences – this was, as Larkin et al. (2019) intimate, less clear-cut than drawing out the themes from the larger group.

Tomkins and Eatough (2010) offer advice on modifications they have applied to their ‘usual’ IPA analysis process when working with focus groups, in order to accommodate and utilise the added dimension gained from working with multiple rather than single participants to the hermeneutic circle of analysis and interpretation. I considered information from authors who have worked with dyads, and also focus groups (for example, Larkin et al., 2019; Phillips et al., 2016). This included looking at the differences between what each partner is living through in both shared and individual experience, and how they related that to me (Wawrziczny et al., 2016). Accounts were also considered in terms of how individuals supported or impeded each other’s explanations, and noting how they made their descriptions meaningful to each other (Palmer et al., 2010).

The words, phrases and expressions, vocabulary, metaphor and emotions expressed by the participants were noted in the dyadic interviews (Phillips et al., 2016; Tomkins and Eatough, 2010). This was focused on times where joint accounts may have differed from an individual account, had the participants been interviewed separately. As advised by Phillips et al. (2016), this included statements that were defending, where a participant would attempt to ameliorate a statement from his or her spouse, and qualifying, where one spouse would clarify something the other said, as well as hedging, where a statement would protect the spouse who uttered it by supporting more than one possible explanation. These authors also advocate exploring pronoun use changes due to different settings. For example, Daisy switched from talking to me to talking to Matt when still discussing the same point, as shown by her use of ‘you’ and ‘he’ in this quote: *“we were talking to you in the car on the way down, and erm, he were, he were like in a right state, you were sobbing, and you didn't know what was happening to you”* (Daisy, lines 301-2). In this way, she included us both in the conversation. Some gentle disagreements were expressed throughout both sets of dyadic interviews and were also noted (Wawrziczny et al., 2016).

Concentrating on the couples’ interactions led to some themes that were individual to each and some that were solely about the couples’ interactions with each other, similar to Phillips et al.’s clustering stage (2016); notes in Tisha and Ajay’s transcript led to emergent themes that include ‘own identity’ and then ‘focus on the other’ and ‘shared experience’: *“we would just lie there and, just cry you know at the thought of losing one another”* (Tisha, line 340). Both the couples’ love and concern for each other was evident throughout both accounts, as evidenced in the following findings chapter.

## Table 10: Key to transcription for findings chapters

| Mark | Meaning |
|---|---|
| - | Interruption in flow of conversation |
| _ | Underlining of individual words or phrases shows emphasis (heard by a change in the participant’s pitch) |
| ? | Question marks show rising intonation that usually produces or indicates a question at the end of a phrase |
| [..] | Pause – the number of full stops indicates the length of the pause in seconds |
| , | Momentary pause |
| ! | Exclamation, conveying strong emotion or feeling |
| … | Ellipses indicate omitted words where the quote has been shortened, so that the most relevant information is presented to the reader |

**In order to protect confidentiality in direct quotes, some potentially identifying features have been removed and replaced as follows:**

[name of person/relationship to participant]

[name of company/type of work]

[name of place]

[name of hospital]

[work/career link]

[media events]

[dates]

# Chapter six: Findings from group one

# Introduction

This chapter, and the one that follows, present the findings from all participants. In this chapter I explore the experience of the participants in group one, whose period of exposure to CO was shorter-lived and most likely in higher concentrations. The findings are presented in three superordinate themes: ‘traumatic experience’, ‘power, justice and judgement’, and ‘identity and connectedness’. The table (table ) shows participant representation in each of these themes. This group, again, in the order that I met them, are Bookie, Vivienne, and the dyads of Tisha and Ajay and then Matt and Daisy. Daisy’s words do not, by and large, form part of the findings here for reasons discussed elsewhere, although she did highlight Matt’s experience and added considerably to the context of his CO exposure and the effect that it had on their family’s lives. It should also be noted that although Matt fits all of the criteria to belong to this group (a potentially very high concentration of CO over a short time period from a generator operating in an indoor space), as he collapsed and was taken to hospital by paramedics, he did not have a blood test to confirm the presence of carboxyhaemoglobin. This difference has had a substantial impact on his experience. Again, for further information about the participants, please see the pen portraits (appendices 1-12).

## Table 11: findings from group one showing participants’ representation in themes

| <u>Superordinate themes:</u> | <u>Subthemes:</u> | Bookie | Vivienne | Ajay | Tisha | Matt |
|---|---|---|---|---|---|---|
| **Traumatic experience** | The one left behind | ✓ | ✓ | | | |
| | Guilt | ✓ | ✓ | | ✓ | ✓ |
| | Traumatic effect | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Power, justice and judgement** | Loss of power | | ✓ | ✓ | ✓ | ✓ |
| | *“No such thing as justice”* (Bookie, line 453) | ✓ | | ✓ | ✓ | |
| **Identity and connectedness** | Identity | | ✓ | ✓ | ✓ | ✓ |
| | Raising awareness | ✓ | ✓ | ✓ | ✓ | |
| | Connectedness | ✓ | | ✓ | ✓ | ✓ |

# Superordinate theme one: Traumatic experience

This theme presents an examination of the traumatic experience suffered by participants due to their CO exposure. The subthemes used to present this theme are ‘the one left behind’, ‘guilt’, and ‘traumatic effect’.

## The one left behind

Vivienne’s partner was a young woman; they were on holiday when the exposure occurred. He awoke, desperately ill himself, to find her dead, still in their bed next to him. The pauses and repetitions in his speech give some indication of the sadness and shock that were immediately present in this trauma:

> *Let’s say it, it took [..] maybe five minutes to, 10 minutes before I was actually capable of [..] clear enough thought to go, ok, something is seriously wrong [..] so, I then immediately turned around, and checked, what was, you know, what was going on with [name of partner] […] and er, what I remember is that she had white foam around her mouth, again, she had vomited, as well, and [..] er [..] erm [..]* (Vivienne, lines 275-8)

Vivienne’s next lines indicate his certainty that she had died, even in his confused and seriously ill state:

> *I’d [..] I’d enough experience, with, death, to very quickly realise that she was dead, em, if I remember correctly, I did try to open her eyes, er, em, and it was all I could rea- I could reach her head without moving, but that was it, erm, and [..] er, but there was- I, I, I didn’t, even need to feel her pulse, or anything like this, I immediately knew she was dead, er [..] but it [..] it then still didn’t hit me to, kind of, ask why, because I was literally capable of one thought at a time [..] and that was a struggle* (Vivienne, lines 288-92)

Bookie recalls that he felt unwell when he stood up after being seated. He was in the living room, and his mother was upstairs in her bedroom. He had the sudden realisation that the central heating, that he had been advised against using by the people who had fitted the cavity wall insulation (albeit in a very offhand and informal way), was indeed on in the house. The following passage details Bookie’s experience of this realisation and his hope that his mother might not have been affected, as he was closer to the boiler. He expresses hope and disbelief; he aligns her slumped position with the very ordinary action of sleeping. However, his phrase *"and that was it"*, conveys that he knew she was already dead:

> *I thought she'll be ok she's upstairs and I'm downstairs [.] I went there and she was just like slumped on the bed like that, I thought, has she nodded off? [..] And sh- and that was it [.]* (Bookie, lines 190-92)

*"Nodding off"* denotes a natural slipping into comfortable slumber. It positions sleeping as an unintentional act; people who 'nod off' do not always mean to surrender to sleep, yet sleep has caught them unawares. This quote indicates the finality of realising that his mother was dead, after hoping that she was *"slumped on the bed"* because she had inadvertently fallen asleep. Bookie then specifies his immediate, shocked response, which along with the rest of his account of this time, has a feel of being somewhat chaotic and fast-paced. He indicates this here by repeating the word *"silly"*:

> *So, I did something silly, I like took me glasses off and put them to her, her mouth to see if she was breathing, you know [.] I thought, and then I thought, you know, do I try to get her round like I did me dad [.] or [.] I've got to phone the ambulance now [.] so phoned the ambulance [.] and I was shouting [.] I said something silly like I think I've killed me mum* (Bookie, lines 189-95)

This last phrase had implications for the subsequent court case between the Health and Safety Executive and the company that fitted the cavity wall insulation. The implications of this last phrase, stated in shock and grief, while Bookie was *"shouting*" for help, will be discussed in the next section.

Vivienne talks about the impact of his partner's death. The two had had a long, happy relationship, and although he says he is not constantly *"in tears"* (line 3235), there are constant, daily reminders of her and their life together, as shown in the following poignant quote:

> *Have I thought of [name of partner] every, day for the last five years? Yeah […] it's inevitable [.] … it's (exhales) it's a particular [..] even, thinking of [.] er- I would like to go on holiday, hmm, [name of place] was lovely, I went there with [name of partner] [.] you know, and [.] there has <u>not</u>, been a single day that I've, not thought of her, … even if I cook something it will be somewhere, in the back of my mind, when I last cooked this for [name of partner]* (Vivienne, lines 3220-34)

Throughout both everyday, humdrum life (cooking meals) and planning something memorable and enjoyable (a holiday), Vivienne is reminded of his partner; his loss of her continues to saturate every aspect of his life. Even when he is occupied with cooking, she is invariably and constantly present at the back of his mind.

Bookie and his mother had lived together after his father (deceased) had been taken ill, and they enjoyed a happy, close relationship. Every death means that any potential future with that person is now irrevocably lost; however, towards the end of the second interview, Bookie talked about their plans for the future, now gone sadly awry, in which he was retired and his mum was still with him:

> *I always used to talk to me mum, I says […] most men die about 73, … Mum used to say, well, I'll still be around, I'd say well, you'll be 97, you've got make your 100, Mum, that was the joke, between us, you know, I said you'll be 97, you've got to make your 100, and if you get to 100 I'll make it to 76 (laughs), it was one of those ones, you know [.] and er [..] it all went pear-shaped* (Bookie, lines 1369-74)

Bookie and his mum's relationship was treasured and their older age was something to be strived for, as that meant more happy time in each other's company. Their mutual expectation was that they would continue as they had done for many years. Bookie reflects on these conversations and how these happy, ordinary plans have gone horribly and abruptly wrong (*"pear-shaped"*) due to her sudden death.

Vivienne's recovery and rehabilitation from the severe injury caused by CO exposure served a useful and insulating purpose for him. Although he perceives that it may *"sound really weird"*, he is *"almost glad"* (line 1400) to have been injured, as:

> *I would have had the full brunt of emotions hit me, all at one time, this way, it trickled in, literally over a month [.] every day my, body or mind or whatever was allowing, a little bit more of that emotion to come in, and, and therefore it came all in bite-sized chunks that I could easily digest, or, well, relatively easily digest ... I felt, really less than [..] half a dozen moments where I felt really, desperately grieving, and I would have expected, I would have expected that to be almost constant, for ages, for literally days or weeks, and that never happened, and it would have happened if it hadn't been for the injury, so, er […] yeah [..]* (Vivienne, lines 1405-13)

It is noteworthy that Vivienne effectively 'separates' himself here – he is recovering slowly and another part of him, his *"body or mind or whatever"* was taking more control of the prevailing, difficult grieving process. The use and emphasis of the word *"brunt"* speaks of the shock of his partner dying and the impact of that loss which, because of the injury, he is aware he experienced 'differently' from what he might have otherwise predicted. Initially, he thought his lack of grief was abnormal: *"I thought what is wrong with me?"* (line 427), but bereavement counselling revealed that he was just in *"pure survival mode"* (line 423) as he was so ill, and that this numbed response was entirely to be expected.

## Guilt

Guilt serves to deepen the trauma of some participants; Bookie held a burden of guilt as he had disregarded the throwaway comments advising him not to turn the boiler on. It was painful for him to relate the following, as evidenced by the pauses and his groan:

> *What I did [.] when it was getting cold, that's most likely why I'm still alive, when it was getting cold [..] it hadn't come on it was still cold, so I kind of, you know you can just switch it up, alter it, so you know you've got clicks, and it's on then, so I did that, I did that just after 8, half 8, you know [...] and er [..] (groans) so then er [..] so then the rest is kind of history [.]* (Bookie, lines 185-9)

Bookie perceived for a time that he was seen as bearing some blame for the situation; indeed, that there was some truth in the *"silly"* remark he had made to the 999 telephone operator about killing his mother (line 195). On consulting a solicitor about the case, Bookie heard the very worst of all news, which further compounded his suffering; the solicitor voiced the opinion that his mother had died as a result of Bookie's own actions. The statement was made by a barrister, an authority figure whose opinion had been sought by the solicitor to help with the decision about the viability of a no-win, no-fee case:

> *The barrister came back with this opinion, that er, em [.] that I wouldn't win in court because, I was, to blame, for putting the heating on? [..] I thought [.] it doesn't get any worse than this [....]* (Bookie, lines 314-5)

Coupled with the barrister's belief, this perception became more complex in light of other people's reactions, which he briefly mentioned:

> *B: some of them got a bit suspicious when she suddenly died, you know, has Bookie escaped? How did Bookie escape? [..]*
>
> *J: oh right, so you felt that there was? [.]*
>
> *B: oh yes all of the peo- a lot of my friends thought, you know, as if they could suggest that [..]*
>
> *J: oh, Bookie [.]*
>
> *B: I know […] yeah we've not seen his mum for a while, you know […]*

At the time, Bookie lived in a close-knit community in which his mother was well-known and liked. From Bookie's perspective, her sudden death had people questioning whether Bookie had some involvement in the event.

Much to his relief, this was later completely refuted by the coroner at the inquest, which happened several years after the exposure. At the inquest the coroner "*looked at me directly and he said [..] you've nothing to blame for yourself, you've looked after your mum, all your life,"* (lines 1170-1). To have an official acceptance of his innocence seems to have made an important difference. Up until that point, Bookie had carried an unnecessary burden of guilt; he did not have a hand in his mother's death, but perceived that others had thought that of him.

Some common ground is to be found here with Vivienne's account, as his partner also died but he survived. Bookie was interviewed by the police for several hours, at the police station, but not arrested. This was not the case for Vivienne; although he is circumspect about what happened and says that he was not *"treated like a criminal"* but instead with *"great, gentleness, and care"* (line 390), being arrested for his partner's murder before it was established that she had died from CO exposure still had a profound effect. Notwithstanding his certainty that he was innocent of causing her any harm, the accusation and arrest momentarily planted doubt in his mind:

> *Of course I had no idea what happened, em, there was a tiny little bit of doubt in my thinking, cos I had no recollection of the night, of actually did I do something? Did I strangle*

> *her, in some bizarre fit? [...] I had no idea, but I very quickly dismissed that from my mind, I honestly could not believe that I would have, err done anything to [...] the love of my life [..] that's how I would still consider her today [..]* (Vivienne, lines 541-5)

Vivienne talked later about this aspect of his experience and its lasting influence on him; *"having these words, that I can still hear, err, today, said to me, of course you start thinking oh my god,"* (line 1396). The words to which he refers as still haunting him are *"Vivienne, I arrest you, for the murder of [name of partner]"* (line 367). For Vivienne, this was frightening, and not *"being treated like a criminal"* seems to have done little to ameliorate this effect. However, Vivienne's professional life as a scientist provided him with a different, respectable identity from that of an arrested man, which could offer him some rational reassurance at that time:

> *That niggling doubt that maybe, even if I didn't do it consciously, maybe I did something sub -unconsciously, I was wondering whether I could have, in any way [.] while normally asleep, I dunno, even accidentally, crush her or something like this, I did wonder … I did go through various scenarios, and if it would have been, and whether or not I could be guilty, of something, so [..]…but it was a, internal monologue, a dialogue, sorry, between the person and the [name of occupation], and the person was going, could that be? And the [name of occupation] was going, no, that really couldn't be* (Vivienne, lines 1768-78)

This other, work-role identity perhaps serves the function of edging Vivienne away from the worst possibilities that surfaced in his imagination at this time, and so it is interesting that he corrects himself when referring to this as a 'dialogue´ rather than a 'monologue'. Vivienne as 'the person' was traumatised and injured and was experiencing *"kind of flashes, almost like, yeah courtroom scenes from films when they popped up, or something like this, you know 'A Few Good Men', and I'm now on trial [..]"* (lines 1783-4). In contrast, the other identity, which was capable of more rational thought at the time, provided cogent and sound advice to support him and operated to soothe his nascent, unnecessary and unwanted feelings of guilt.

Although Vivienne and Bookie were the only participants to suffer a bereavement, they were not alone in experiencing guilt. Tisha suffered extreme feelings of guilt as did Matt. Rather unusually for both of the groups, Tisha's guilt is connected to her lack of knowledge about CO at the time of the exposure. She feels that she should have known to buy a CO alarm as they moved into the flat, but *"it didn't even cross my mind"* (line 1167):

> *You know, I do think that, of all things, that, if I had all knowledge of all the things I could have done, I could have had that, it would have saved us so much pain* (Tisha, lines 1169-70)

Matt's remorse and feelings of guilt have somewhat different characteristics, as he blames himself for several reasons. The first is connected to how his exposure happened at work. He describes himself as a conscientious worker who was *"taking precautions"* (line 1596). He needed to use a generator provide him with a source of electrical power to conduct some repairs in an empty property. He worried that a generator left outside the property in which he was working alone would be stolen, although leaving it outside would be safer for him. In line with the then accepted practice at his place of work, he used the generator inside the property. Although he took precautions as far as was practicable, he appreciated that he was putting himself in some danger, the nature of which was difficult to estimate. A much later conversation with a third party brought up the possibility of suing his employers for allowing this practice:

> *But I never thought about it, because it was my fault to be honest, it was my fault, I'll hold my hand up (sighs) you know, I-I I was, you know, sort of grownup enough to know, you know, I wouldn't blame, my boss, … it was just a decision I made, you know, simply because I was, conscientious, you know, (laugh) I don't want someone pinching the generator* (Matt, lines 2261-5)

It is entirely possible that people who had previously been in this position at work have had some effects of CO exposure over time. However, these dangerous working practices have since been changed, so Matt's choice of present tense here, *"I don't want someone pinching the generator",* after relating the incident in the past tense up until that point perhaps reveals that it is something over which he still ruminates. His use of *"grownup"* here refers to a mature person who is able to realise that the responsibility for the exposure belongs with him alone. The laugh he gave when describing himself as conscientious indicates that, in hindsight, he feels his diligence was not worth the risk he took; he would rather the generator had been stolen than he had been exposed.

Matt’s employers eventually changed the practice around working with generators in properties after a younger colleague of his died in similar circumstances, working alone in an empty property, with a generator. There are some questions around whether this colleague intended to commit suicide; Matt recalls talking to him about his own experience:

> *I course said, oh, blooming heck , you know, has he [.] taken something from what I've said? … I was telling him, to be careful, don’t, don't have it in, you know, don’t have it in, wherever you’re working, don't have it in, you know, just leave it outside [.] and then, then that happens, you know, and er, I mean I’ll just never know [.] but [..] I’m thinking, oh, blooming heck, you know, has he sort of thought, … I'm going to end it, and, that seems the best way? You know, it's, not good, is it ?... It's [.] like, too much of a coincidence* (Matt, lines 2312-20)

Matt had urged this colleague to be careful. Shown here through his repetition of *“don’t have it in”* (the generator) and the interjection *“blooming heck”*, coupled with *“It's [.] like, too much of a coincidence”*, the thought that he may have provided his colleague with an idea of how to kill himself is shocking and disturbing to him, and a considerable burden to bear.

Matt also experienced feelings of guilt and remorse for his situation due to what he perceives as a failure to be taken seriously about the cause of his collapse at all stages of the experience. He perceives this as caused by his own inability to communicate his situation forcefully enough, rather than any ignorance or disbelief on behalf of healthcare professionals: *“why the hell didn’t you say to him, you know?”* (line 99) – the ‘him’ being the A&E doctor who diagnosed syncope, being unaware of the presence of the generator and thus of the true circumstances of Matt’s collapse.

## Traumatic effect

The realisation that they had been exposed to CO constitutes a traumatic experience for the participants, which inevitably had a psychological impact in conjunction with the physical effects. One of the immediate concerns was dying from the exposure. Matt, through his repetition, highlighted how difficult and frightening his isolated situation, working alone in an empty property, was:

> *I was thinking, I don't want to die here, you know, there's nobody knows I'm here! [.] It sort of come to me that, nobody knew where I was [.] you know, and I thought, I don't want to die here, and I thought, what's going to happen, am I just going to have a heart attack or something, that's what I was thinking, I was thinking I was just going to, go at any minute, and I thought, no I don't want to die here, so what can I do* (Matt, lines 57-61)

This was a severe dread; Matt repeated that he doesn't *"want to die here"* three times. When Matt mentioned a heart attack, he was indicating how ill he felt. He appreciates that he narrowly escaped death, as the generator had been removed by the time he collapsed: *"if it was something, still going, then I, have no doubt about it I wouldn't have woke up or I'd probably would have just passed away or something [.]"* (line 1682). He emphasises this point often; he made a phone call to his wife to say goodbye to her, as he did not think that he would see her again. Both Matt and Daisy referred to this conversation throughout their accounts.

Tisha describes being *"shell shocked"* (line 608) to convey how the trauma impacted her and Ajay. Another war-like metaphor, shell shock speaks of how damaged this dyad were by the trauma, creating a strong image of devastation on a battlefield. The expression refers to soldiers from World War I who were suffering from a type of PTSD from the constant bombardment of exploding shells and from barely escaping death every day. Tisha realised that she had come close to death, as healthcare professionals established, once the exposure had been recognised, that she had a seizure on the Sunday morning (the CO exposure was identified on the Monday). She was shown a graph in hospital with stages of CO exposure symptoms, and said that:

> *The next stage after that is obviously what- luckily I didn't have which, is, you know, death, and that kind of, puts it into perspective, really, how close, how close we were"* (Tisha, lines 856-8).

Some of Tisha's trauma comes from the fact that she was admitted to A&E with unrecognised CO exposure the day before, during which the chance to identify the true cause of her symptoms had been missed. She and Ajay had subsequently been sent home, where they continued to be exposed to CO:

> *Seeing that on the graph is […] I don't know quite scary really, and the fact that we were back there the next day [.] and I'd already reached that point […] you do wonder how you got through it all (slight laugh) and whether you're supposed to get through it all* (Tisha, lines 1048-50)

Tisha was very open in talking about her struggle with thanatophobia, a phobia of death and dying, which was present before but became more substantial after the exposure. She sought therapeutic support for her fear, which remains with her:

> *I have a massive phobia of death, and anything associated with death, every single counselling session was very much like, this could have happened to me, this has happened to me this, is how I'm feeling, why me? And you know, those, traumatic events have created traumatic emotions that have seemed to kind of stay [.]* (Tisha, lines 569-72)

For Tisha to ask the rhetorical *"why me?"* question could be considered a sign of emotional conflict caused by her trauma, a conflict that remains troublesome. Tisha talked about the artistic representations she made of her trauma. Her repetition of the word *"torture"* indicates the depth of her feelings here; she needs to express the extreme psychological pain that is the consequence of her trauma, which was perceived as brutal and terrorising:

> *I'm here I can't get out I'm being tortured, the hearing the loud noises are torturing me, the pain and the trauma from what we suffered are torturing me, em [.] at one point it was even just seeing Ajay was torturing me, because he's the one that I went through this with, em [.]* (Tisha, lines 1728-30)

Tisha has hyperacusis (in which ordinary levels of noise are perceived as being very loud and painful) as a diagnosed consequence of her exposure. For this, she was given extra sessions of hyperbaric oxygen therapy, which she found to be very burdensome and not especially beneficial: *"for every one that I had to go to, I was just like, I can't wait till this is over I can't wait"* (line 1603). In addition, Tisha and Ajay are a close couple, who were newly married at the time of the exposure; stating that his presence felt like *"torture"*, that she felt that his presence provoked an extremely painful reaction, speaks strongly of her distress.

Tisha's artistic representations of her trauma were made in a *"pure state of anger"* and were drawings of the dementors from the Harry Potter stories:

> *“I was drawing those, without realising in my pure state of anger I was drawing those, and, er [.] they were kind of flying around with me in a birdcage, inside, a kind of, tiny timid version of me in a birdcage”* (Tisha, lines 1726-8).

This powerful image shows how small and helpless she felt in the face of her traumatic experience. Dementors are wraithlike creatures that feed on human happiness; this diminutive, powerless version of Tisha, trapped in a birdcage, indicates that she longed to escape the dark confines of her trauma by flying away, but thought that she could not.

Ajay responded differently; initially, he was *“probably in shock”* (line 273). He also, in that immediate period, experienced anxiety and felt that it was *“difficult to cope”* (line 1498). He talked about the difficult aftermath of the trauma, which he had to endure while physically recovering from the CO exposure. He acknowledges differences in their experiences but still validates Tisha here:

> *I think for me, I think, like Tisha said after, I think probably for a good few months after, our relationship really suffered, because, we were both very very, still very unwell and still, mentally we were struggling to be able to, cope with the severity of what happened? I remember we argued, and slammed doors a lot, and you know, stormed out* (Ajay, lines 1539-42)

This was after returning to work and seemingly presenting to other people as ‘recovered’. As there are no visible signs of trauma, the couple perceived that their ordeal was something that the people around them did not always appear to appreciate was happening.

> *It’s things you can't see, you can't see the brain damage, you can't see the em, hearing, unless you physically see me cringe , you can't actually see, you know, the damage, in the flat you can't see like a blackened wall or anything like that, so there are no visible signs of, any of the damage that happened, everything is basically in here, in the brain, and [.] that's really hard to explain to people* (Tisha, lines 555-9)

Bookie expressed fear when talking about his overnight admission to hospital. Despite his condition, he would not let himself go to sleep, viewing staying awake as his only option for staying alive. He also talks about his grief at this time:

> *I wouldn’t- I refused to go to sleep [.] you know I was (mimes breathing difficulty) and I had this mask on, and they says, you know, try and get some sleep, and I said no I'm not falling asleep I’ll never wake up again [.] you know [.] … I was facing, you know some drunk they brought in … and he says, sometimes I wish I was dead and I just shouted across I wish you*

> *was an all, and not me mum [.] that big bloke just glared at me [.] so that's how bad I was, … (laughing) and I said and this poor guy, you know, and I wished he was (groans)* (Bookie, lines 831-40)

Bookie now indicates remorse for this out-of-character display of emotion, which may have been a sign of his traumatised state at the time. There may also be an indication, as the disruptive patient was a *"big bloke"* that Bookie's utterances could be seen as confrontational. The situation was so extreme that he did not seem to care about this at the time, but with later consideration he has now come to regret his outburst.

Bookie later attested to *"patches"* of thinking *"I just wish I'd gone with my Mum"* (line 1402). This clearly shows the impact of the trauma. Tisha also, in an argument with Ajay soon after the CO exposure, stated that she wished the event *"would have just taken my life"* (line 1529). The aftermath of exposure is truly burdensome; these expressions of not wanting to live anymore, because of CO exposure, express the despair felt by some participants.

In addition to the trauma of the death of his partner and the CO exposure, Vivienne suffered the most immediate physical trauma of all of the participants, which included near-amputation of his arm, a prolonged hospital stay and a protracted and complicated rehabilitation. However, he expressed his feelings around the trauma of the closeness of his own death in the first interview (and therefore without any prompting from me) perhaps more factually than emotionally; he first disclosed the subject when talking about how his friends and family worried about him and cared for him when he was still in hospital:

> *Because I was about as close to death [..] as you can get [.] I don't think there are many people who survived a closer call than that, certainly not in carbon monoxide- but, even in general* (Vivienne, lines 757-9)

As I was interested in this aspect of his experience, I prompted Vivienne about this during the second interview, asking if he had any more he wanted to say about his physical condition. He told me that he felt close to death when he first woke up; which was of course when he discovered that his partner was dead and he was in dire need of help but isolated, meaning he had to try to shout and telephone for help. Once he was being cared for, he actually felt *"okay-ish"* (line 2648) as he was receiving treatment; he did not recall thinking about his own death in hospital. This may of course be connected to what has already been discussed about survival mode; that Vivienne was so physically ill, all of his resources were concentrated on surviving. His hospitalisation was followed by intensive rehabilitation and a long, difficult recovery time.

Returning to the subject of the trauma caused by the death of his partner, Vivienne's loss was powerfully brought home to him shortly after his admittance to hospital in a particularly poignant way. His partner worked in criminal investigation. As part of the police investigation, he had to provide clippings of his nails. The clippings were taken by someone in the same job who *"looked, almost like [name of partner]":*

> *Why this was so hard, was, that [.] [name of partner] had never clipped her own fingernails … [.] and therefore, … when she became a [name of job], she had to kind of do this to others [..] er, living and dead people, and she was really panicky about this so she trained on me, … [..] so I'd literally sat through that procedure several times, with her, in our kitchen [.] and now, you know, there was someone doing that to me, and I knew that she would have done this, just a week earlier to someone else [.] … and that was pretty tough, ah [...] erm, emotionally to take,* (Vivienne, lines 414-21).

He perhaps specified *"living and dead people"* here as it is likely that this same person, who so reminded him of his partner, had also had to clip his partner's own fingernails in the mortuary of the same hospital. This act, which had been a shared, intimate occurrence between Vivienne and his partner could now never be repeated, as she could never touch him again. He was also, perhaps, forcibly reminded, by someone who resembled her and in the same profession, that she (his partner) may have performed this procedure recently but would never again do so.

## Superordinate theme two: Power, justice and judgement

The notion of justice as the administration of the law in maintaining fairness applies to some of this group, but not all. Matt and Vivienne were not in a position to seek any sort of legal compensation for what they had suffered due to the contexts of their exposures. This theme therefore presents the experience of Bookie and the shared experience of Tisha and Ajay in terms of justice, and Matt in terms of power dynamics. The subthemes are ‘loss of power’ and ‘no such thing as justice’.

## Loss of Power

Power operates on many levels. It is possible for trauma to contribute to a sense of powerlessness, as perhaps evidenced in Tisha’s artistic expression of her perceived powerlessness in the face of her trauma, using the dementors’ trapping of her to depict the aspects of the experience that she found most difficult to bear. Matt’s experience around power is important here, however, as he is juxtaposed with the other members of this group as someone who does not have his health problems recognised as being caused by CO exposure, as he is, essentially, self-diagnosed. This situation came about due to the power dynamic that exists between healthcare professionals and patients. The cause for Matt’s initial collapse was dismissed by the attending paramedic – in his weakened state he still managed to say that there had been a generator in the property, to which the response was *“oh I can’t smell anything”* (line 82). He was also triaged incorrectly despite giving the same information to the triage nurse. The doctor at A&E therefore discharged him, as previously mentioned, without considering CO as a cause for Matt’s collapse:

> *I blame myself, you know, I told the paramedic, there’s a generator there, I told the nurse, by then that it was, carbon monoxide, and you beat yourself up, well, why didn't I just say to the doctor? I just assumed, you know, in my state of mind then, and I just totally assumed that he’d given the details [.]* (Matt, lines 532-5)

Matt holds self-blame for this situation, whereas he could, perhaps, instead, hold the healthcare professionals responsible for not imparting the right information and not diagnosing him correctly. He returned to this expression of regret several times over both interviews, saying *“I never learn, I never learn”* (line 859), and wondering whether being more forceful, or approaching the situation in a different way, would have led to treatment for him and perhaps even an avoidance of his current symptoms:

> *I think you always do, you know, you think, oh, flipping, why didn't you just say that, you know, and you beat yourself up over it, because that would have been, the defining moment , and the treatment, you know, that might have got me some [.] some, a different outcome,* (Matt, lines 1942-5).

Some time after his exposure, Matt describes consulting his GP about his anhedonia (his inability to feel pleasure; an affective symptom from CO exposure). For Matt (and Daisy) this affect was directly related to the exposure. He also details the consequent feeling of being ridiculed by the GP for stating that his symptoms were a result of this CO exposure. The GP's reaction led to Matt leaving the surgery feeling dissatisfied:

> *He pretty well laughed at me, put on me notes, thinks he's had, thinks he's had carbon monoxide poisoning [.] so [.] I (exhales) sort of [.] sort of laughing at me, in that sense, he's some sort of, you know* (Matt, lines 1760-2)

Matt was asking for help, but he felt rejected and that he was suspected of experiencing a psychological disorder with no physical basis. *"He's some sort of, you know"* indicates that Matt is a fool, weird, or deluded. Being laughed at in this manner, feeling as though the doctor thought he was *"stupid"* (line 421) for having thoughts about his own health (ascribing his symptoms as sequelae of CO exposure) has had an enduring negative effect; *"it just knocks you right down, doesn't it?"* (line 575). Matt's frustration about his 'supposed' ailment (as the GP saw it) alludes to a particular power dynamic that often features more strongly with participants in group two whose CO exposure also was unrecognised over varying periods of time. Of course, there is no way of knowing at this juncture whether the GP in question was aware of neurological and affective sequelae as a result of CO exposure, or indeed any of the issues that surround those who have been exposed. He may have thought that Matt's initial collapse was just, as reported, syncope, and that he was, at the appointment, displaying completely separate, and common, mental health problems. There may also have been the suggestion that Matt, as someone without medical knowledge, thus has less power than the GP and is unable to know more about his own health than a GP, or even have the right to make such a judgement about it. This shows the difficulty inherent in trying to resolve situations around CO exposure.

Most participants in this group expressed a drive to change the situation regarding both their own exposure and the existing state of affairs around CO exposure in general, due to the trauma that they had experienced. Matt had *"episodes where I've wanted to pursue it"* (line 135) meaning he wanted to have his symptoms of exposure investigated and has been in touch with various healthcare professionals, including a doctor at a hyperbaric chamber. As have many of the participants in both groups, Matt has taught himself a great deal about CO exposure and its effects.

Vivienne also found that he was powerless to stop news of his arrest from being publicised. While there is discussion of media as a vehicle to raise awareness about CO exposure in a later section, there is a particular aspect of media involvement that belongs in this theme, as the experience shows how people can lack control, and also how they can use media as a device to regain control.

The death of Vivienne's partner and his short arrest were considered newsworthy; the reporting of the incident led to what was for Vivienne an appalling situation:

> *Actually the [name of newspaper] hacked, [name of partner's] Facebook account to get pictures of us [.] and my name because police had withheld my name, and it was in the [name of newspaper] that I was arrested for her murder [..] and they never did a proper, oo sorry everyone, we got that wrong* (Vivienne, lines 734-6)

*"Hacked"* signifies unauthorised access to the social media account, but the word in its original meaning of being violently cut to pieces also conveys something here; that after her death, his partner's privacy, and his good name, were worthless, trifling considerations that could be treated in such a way. Vivienne also could not control this intrusion into his life and he found this very distressing. His de-arrest, when the cause of his partner's death and his grave illness came to light, was also not reported correctly; the paper said that *"there was insufficient evidence, and that is very different"* (line 2377); members of the public who read this article may have perhaps thought that he was guilty of some wrong-doing but the police did not have grounds to pursue the case. Therefore, in addition to his bereavement and severe illness, Vivienne had to contend with a potential slur on

his reputation. As this is an online publication, the material is still accessible; the passage of time has not altered the false information:

> *You can see that immediately, somewhere at the top, and it's still at the top- the [name of newspaper] still comes up really high on Google* (Vivienne, lines 2681-2)

The existence of this piece of journalism serves as a constant reminder of that lack of control, as well as the loss of his partner.

A further example of media and the sense that power dynamics are innate in any relationship with them comes from Vivienne. Although he perceives that the majority of his interactions with media have been positive, Vivienne also had what he describes as a distressing encounter with a reporter who he felt had already deduced what had happened and did not seem to desire any genuine interaction with him, having, essentially, already written the story. This quote also speaks directly of the trauma of finding his partner and of the seeming disrespect of that person, who was:

> *The weirdest, and rudest [.] er, reporter I've ever met [.] she had already, I mean she was one of those reporters that had already written the story, before she ever, started asking the first question [.] you can tell straight away [.] they just wanted to- to- to tell you, they just want you to, erm, say yes to what, they already think happened, and she, constantly interrupted me I mean I'm right in the middle of explaining how I felt that my partner, you know, in her own [.] vomit and she, keeps on, wandering off and asking me other things, I mean, that was just, really rude* (Vivienne, lines 2714-20)

He is clear that this experience was an aberration, however, and states that the more positive experiences he had with media personnel were beneficial and ameliorated the negative effects of the hacking event: *I think it was that overwhelmingly good experience that helped me cope with the [name of newspaper]* (line 2727)

Tisha and Ajay talked about regaining a sense of power which they felt they had lost, when they discussed their involvement in media campaigning. Speaking for both himself and Tisha, Ajay states:

> *I think for me, like, a year after, you probably saw we did a lot of media work, erm, and er, that's how it was like for both of us, closure, so it was a year, exactly after our incident? And erm, talking about that, I think gave us a lot of pride, because instead, of otherwise, I think we would have basically been very emotional and just upset* (Ajay, lines 594-7)

Ajay called the media work *"ultimate closure"*, as it marked the anniversary of the exposure in such *"a positive way"* (line 1585). Tisha agreed, stating:

> *It just made that anniversary something productive and something proud to feel, rather than thinking about what actually happened, and only wallowing about it, so, you know, next month when it comes to two years, we'll be thinking about our media interviews … rather than you know, the unfortunate events completely taking over, everything, … so we've turned it into something powerful but, that has taken a long time to do* (Tisha, lines 598-602)

In emphasising this point, Tisha also speaks for herself and Ajay when she states:

> *Through doing all of those things do we feel like that emotional load is lightening and we're doing something for, other people, you know, which we couldn't do to, protect, ourselves [.]* (Tisha, lines 588-9)

## *"No such thing as justice"* (Bookie, line 453)

Tisha and Ajay contacted some lawyers after realising that the property management company may have had some liability in what happened to them. This turned out to be neither a fruitful nor even a pleasant endeavour for them, as they found that the lawyers were largely not helpful. Despite contacting lawyers who had been recommended, these lawyers were described as *"aggressive"* (Ajay, line 676) and *"cut-throat"* (Tisha, line 677), with one notable exception who informed them that the deceased owner of the flat downstairs was the only person who could be considered culpable. However, substantiating his culpability would be extremely difficult, as they would have to:

> *Prove in court, that you, that he, was aware, that his gas fire was faulty, he was aware that it would cause harm to both himself and others, and he, wilfully, didn't do that* (Ajay, lines 695-7)

This realisation caused further conflict for the couple, as Tisha expressed anger and upset, initially, at this:

> *Because, you know, you do automatically think someone needs to pay someone needs to pay, it's not fair, I didn't deserve this* (Tisha, lines 1549-50)

This theme is crucial for Bookie, as the court case around the installation of the cavity wall insulation was protracted and difficult. Bookie felt all of his battles were around the justice system and that this had been detrimental to his ability to grieve for his mother as it had complicated the process:

> *It's just that it's gone on for this long, and this long, and that's what's made the worst of it, you know, I still have, everybody- everybody's parents die, and everybody gets over it, you know, I've lost my brother, I've lost mates, I've lost every relative [.] but this one I can't get over me mum because it's [..] the injustice of it […]* (Bookie, lines 767-70)

Bookie was not interested in seeking monetary compensation despite only having a small income, as he was unable to work; he stated several times that he would have been happy if he had just been reimbursed for having to pay to have a new boiler fitted, but the case was complex. He wanted the company responsible for the cavity wall insulation scheme to be sued for corporate manslaughter and was clear that he laid blame for what happened with the man who set up the company. However, his lawsuit did not resolve as he had hoped. It took three years for the inquest, after which Bookie's mother's death was ruled as accidental. His experiences with the legal system, despite his feeling that there were some individuals within the system who were good to him, led him to the belief that *"lawyers, just want one thing, money [.]"* (line 374), which resulted in more pain for him:

> *I had to go through it all in front of <u>again,</u> in front of […] I don't know, is there a jury there, I think there was a jury there [.] I know I was in tears again, I was thinking why am I going through it all again* (Bookie, lines 403-5)

Bookie recalled the emotional impact of recounting his experience during this court appearance, without being able to remember the details of the events. He was clear that he wanted me to tell other people in the same situation to *"stay away from lawyers"* (lines 509 and 658) because *"they're just ambulance chasers"* (line 463) and *"it's all a game to them [.] they meet up and shake hands afterwards"* (line 515).

Ajay also used the term *"ambulance chaser"* (line 1812), which defines lawyers as stereotypically profit-driven and grasping. Bookie found the whole system too difficult over which to assert any form of control or autonomy. His perception is that someone can only 'win' if their lawyer is *"better than that lawyer"* (line 508). In his assertion that lawyers prioritise only money, Bookie is saying that they cannot care about other things; in his case, the human suffering caused by the negligence. Throughout both interviews, he showed that he has a different mindset from the lawyers themselves and sets himself apart from them. He remembers being told *"there's no such thing as justice [..] and, he says, you'll never get justice"* (line 453) by a barrister, and he feels that this is an accurate summation, as he perceives that he is a *"victim of injustice"* (line 1407).

The quest for money led the company's defence lawyers to try to discredit Bookie, calling his integrity into question and naming him a *"tortfeasor"* (wrongdoer) (line 1135). He was warned that they may follow him in an attempt to gather evidence that would support that position, *"so I'm looking over my shoulders and everything"* (line 692). Even though he was talking about the past when he said this, and the court case is completed, Bookie's choice of tense here reveals that for him, the tension from thinking that perhaps he is being spied upon may be ongoing. It seems as though this stressful aspect of the exposure has influenced Bookie's perception of the whole situation. While we were having a break from the interview, he showed me some of his paintings; part of one referenced the Sondheim song, 'send in the clowns' and had 'maybe next year' written on it. He said that this was in reference to the lawyers, stating that at the time his pursuit of justice had seemed endless.

## Superordinate theme three: Identity and connectedness

Following an exploration of ideas around 'identity', the motivation for participants to campaign with charitable organisations and engage with the media in order to disseminate the message about CO will be discussed in this section. Both of these points support ideas of connectedness with regards to the participants' experience of CO exposure. A sense of connectedness and fellow-feeling can both support the participants and allow them to feel that something positive can be derived from their trauma. This will be presented through the subthemes of ‘identity’, ‘raising awareness’ and ‘connectedness’.

## **Identity**

This subtheme explores that which has been taken away from the participants’ sense of self, and how they have had to struggle to regain what they could. Participants felt that the trauma of CO exposure and its aftermath was so profound that they no longer knew quite who they were. Tisha has memory issues and hyperacusis; for Ajay, this cast doubt on their future and found him questioning his role as her husband:

> *I'm not sure whether, like, for example, I'll have to like permanently have to look after Tisha, how that will affect us, you know, is it something that's going to get worse”* (Ajay, lines 1638-9)

Tisha, too, felt that her sense of who she was as Ajay’s wife was adversely affected. She was also used to helping her mother, who has a chronic illness. The inadequacies she felt, because she was not able to perform the roles that she normally performed, had a distinct effect on all aspects of her life. She was left feeling as though the roles that she normally performed and the names that came with those roles were the things that made her herself, and she did not know who she was without them. She felt as though she was perhaps deficient in some way, and that her very body was failing to support her identity:

> *As a wife I felt inadequate, you know? I'm so used to, like [.] being at home early … doing the cooking, the cleaning, just making sure that everything was nice and ready, and I couldn't- I couldn’t do any of it [.] I couldn’t even help my mum at home, I could- I just physically couldn’t get up, and erm, you know, as a woman, as a wife, as a daughter, I just, didn't feel like I was worth anything to anyone at that point [..]* (Tisha, lines 1642-6)

Vivienne’s injury to his arm was extreme, but he was so ill on waking when he was exposed to CO that he did not realise this initially; when he did, he felt as though he had *“virtually no right arm […]”* (line 335); as though his body was not the complete entity it had been when he went to sleep on the previous night. As discussed in Vivienne’s pen portrait (appendix 5), there was a debate between his doctors about the best course of treatment, and amputation of the arm was seriously considered. As well as the other impacts this would have had on his life, he appreciates that he would have had to change his career if that had happened and so he is *"extremely grateful"* (line 2084) that it did not. Through work and career, people can derive a sense of meaning and identity. There was a protracted recovery and rehabilitation process for Vivienne, and a secondary condition developed as a result of the injury, to which he has become *"'basically resigned"* (line 2562).

Returning to work after such a trauma was an inevitably lengthy undertaking and he did not perceive the provision for phasing him back to work to be supportive. There is a particular task considered to be one of the *"key things"* (line 942) about his work, which he was *"really really keen on still doing"* (line 948) as one of his *"key, aims, in recovery"* (line 949). This was perhaps symbolic of something more to him than a commonplace part of his job: *"to me that was the goal, that was the test"* (line 957) of his recovery and return to normal functioning; however, permission to perform this task was initially refused by his place of work's occupational health department. He persevered and can perform this task now, but remains concerned by the perceived attitude of that department. 'She' and 'her' refer to the occupational health worker in this following quote, where he says that he would have expected someone to:

> *watch me [.] and watch me in here [.] sit in the corner and look at what I'm doing and how I'm doing it, and then suggest – no, she's never been in this room [.] tell me to, I don't know, get a different chair, come out, to the [name of task] and see what I'm doing there I would have expected that [.] … I had three sessions with her, and, they were just [..] pointless* (Vivienne, lines 2869-73).

Vivienne was, overall, cautious about stating that his identity had changed profoundly because of his experience, as he can still work in the same job. He suggested that had he been *"labelled or classified as disabled"* (line 2764), this may have been different for him. He stated that he had the option for such a classification, but *"didn't want to risk it"* (line 2767) as he may have been treated differently and some of his choices would have been removed – he felt that he would not have had the same level of autonomy.

Vivienne does talk about a concept that others have asked him about, that of gaining a *"second life"* (line 2649) when he has been asked if the experience has changed him:

> *I think there is a perception that, er, that a lot of people think, now you've got a second life, and- I mean people have asked are you doing anything differently, and I went- so do you think I was a bastard before?* (Vivienne, lines 2649-51)

Again, Vivienne talks about a difference, a separation, of different aspects of himself, in this context, when talking about a common reaction to such a life-changing trauma:

> *I don't think, that I'm a different person now, really, than I was before, I mean it may have, no not really appreciate life more, I know that's something that a lot of people seem to say, but, one thing, that, it does have an effect* (Vivienne, lines 2659-61)

He, Vivienne, sees that he has changed in terms of risk-taking; he doesn't think that he has *"eight more lives"* (line 2664), metaphorically aligning himself with the way that cats are perceived in the proverb about them having nine lives to be able to survive dangerous situations, although he does not state that this change is definitely because of the experience.

Matt's unrecognised sequelae have had significant effects, as detailed throughout this chapter. For him, the worst part is his anhedonia. His succinct summation of how he feels all of the time is that: *"nothing means anything"* (line 127). He comments on his continually emotionally flat state: *"I'll be tomorrow, like, I am today [.]"* (line 1790). He no longer experiences any of the joys and sadnesses of family life; he has become an observer, even though he remains a central figure.

Matt noticed soon after exposure that he was having problems with his memory and using machines; perhaps the fact that he noticed this first is to be expected if his mood was emotionally dulled. The former issue led to poor motor skills and poor adaptation of those skills when it came to determining how to use everyday implements. The example that both he and Daisy returned to was an episode with the drinks dispensing machine, where he brought Daisy a cup of *"half tea and half coffee"* (line 110). What is striking is that she has never, in all of their long relationship, liked tea, but often drinks coffee. This is therefore perhaps a small, yet for Matt and Daisy, significant and distressing instance of the damage that CO has caused to Matt and his family; he ‘forgot’ something simple about his own wife, evidence of which he usually saw every day.

Daisy often talked about the differences in Matt, saying how everyone around him was concerned at the changes in his emotional state and his behaviour. She worried that she would become his carer, as Ajay also feared he would for Tisha, and that she no longer knew him. This was something that Matt found difficult to convey to me; his suggestion that Daisy should be included in the interviews was prompted by his perceived recognition that his lack of emotional affect led to difficulty in talking about his mental and/or emotional state. They both agreed that he was like *“a different person”* (line 1812) after the exposure, with Matt asking Daisy to confirm that the change was significant several times throughout both interviews. Daisy talked often about the ‘old’ Matt and ‘this’ Matt. In the following quote, Matt eloquently expresses the chaotic and unsettling nature of the situation that has led to his altered identity, talking about the fundamental changes that he has experienced and the effect that has had:

> *You look the same, but you aren't the same, are you? You haven't died, and you haven't been, where they can just put a plaster on it, but, but, mentally, you’re chucked all over the place* (Matt, lines 3411-3)

Despite his unchanged appearance, Matt’s perception is that he feels radically different. He likens his injuries as being somewhere in between two extremes, that of death and that of a minor and superficial graze that could be treated with a sticking plaster while it heals. He feels that his exposure has left him *“all over the place”* – in a metaphorical space where he is dazed, scattered and unable to comprehend what has happened – and that he has no agency in this, having been *“chucked”*.

Tisha is clear that she does not want to completely forget being exposed to CO, even though she and Ajay have worked positively to engender feelings of closure. She feels that her identity has changed because of the experience, despite the sequelae that she endures:

> *I want to, remember, I want to, stay connected with it, I don't want to just, put it under the rug and forget about it forever because, that has changed, the definition of me, and, how I am now in comparison to how I used to be* (Tisha lines 1973-5)

## Raising awareness

A drive to change the status quo has seen some participants campaigning for CO charities and engaging with awareness raising, including media appearances, as they hope that more publicity and awareness would lead to others not experiencing this trauma. This particularly applies to Vivienne and Tisha and Ajay in this group. In addition, increased publicity is something that could reveal any wrongdoing, as Bookie states, when referring to the man behind the company who were responsible for the negligence in his situation: *"the only way you can highlight people like this guy … is by exposing them in the media"* (lines 1186-8). Raising awareness through campaigning about the dangers of CO serves a secondary purpose here. As well as the aim of preventing CO exposure for others, there is a clearly perceived positive emotional impact from doing such work. Ajay described a continued positive affect from working with a charitable organisation and discussing his and Tisha's experience; for him, such work is important as a means for other people to hear about what happened to him and Tisha and they will then know how to avoid the situation. In this way he shows concern for and connectedness to others. Ajay also discusses moving away from the trauma of the exposure towards something positive:

> W*e've made it our kind of almost life goal to try and er, use our experience to our advantage and let people know through media or through events we do, or even just little things, like talking to people? Just like we are now* (Ajay, lines 581-3)

Talking to the media is beneficial to Ajay and Tisha as well as others, while campaigning allows for closure and affords them pleasure and satisfaction. They take pride in wanting to help others avoid what they have been through, but also find a valuable purpose in just talking about the experience to others.

Tisha emphasises that talking is a *"healing process"* (line 1971) for her; that she finds release in recounting the experience. Tisha talks about the *"awareness route"* (lines 566 and 663), as opposed to seeking justice, in that she felt that she could have chosen one or the other as a way of coping with her trauma, and finds satisfaction in her chosen route of awareness raising. For her, this particular route seems to bring about more peace between her and Ajay; *"all I wanted was, for us to be happy solid, emotionally, connected again"* (line 664). Additionally, she presents her thoughts on the research itself; *"I'm so glad that you're doing a PhD on this, I think it's so important"* (line 804).

Raising awareness though communication of the experience was initially difficult for Tisha, but like Ajay, she saw it as something important. Immediately after the exposure, when things were at their most problematic, Tisha recalls that she found it difficult to talk to Ajay, even about what they had been through: *"Ajay would get very frustrated because he would say talk to me, just talk to me,"* (line 1576). She did recognise a desire to communicate their story, however, and it was she who contacted the charity and initiated their role as campaigners. The 'she' here is the charity director: *"I went on to the [name of CO charity] website, and I wrote our story … by email and she got back to me"* (lines 1770-1).

Vivienne shares some of Tisha's perspective, saying *"as hard as it is to talk about the whole thing [.] it does actually help, as well"* (line 936), although for him this was viewed through a lens of the burden of grief. Some of his motivation for talking about his experience comes from trying to make sense of the vagaries of his experience: *"why did I not die and [name of partner] survived"* (line 1295) as well as a desire to combat lack of knowledge. For Vivienne, campaigning and raising awareness is also about ensuring that his experience is not being repeated by someone else who does not comprehend the dangers of CO; in addition, one of *"the things that now drives me"* (line 533) is supporting services such as the police to be able to deal with any similar incidents effectively. He also shares Ajay and Tisha's idea that talking about the experience is beneficial:

> *So [.] confronting, er, something that has happened to you, and it's, not just, brooding about it internally but trying to actually address it, er, in one way or another by either telling others or by writing it down, reading it yourself, you know, there's no doubt that you, to a certain degree distance yourself [.] a bit, a little bit emotionally, so [.] I think that's probably, one of the reasons why, I don't mind giving interviews and so on [..] er [..] and, yeah you [..] there's*

> *also a certain [.] duty aspect, that, it's now expected of me, and therefore I started it, so, I have to finish it, erm […]* (Vivienne, lines 1339-44)

Vivienne states that talking about what happened has generally become easier over time, but that he sometimes feels as though he is *"really struggling [.] ah, to, to, say it all out loud, not to, get emotional about it [.] in other, scenarios, I can, talk about it, as if it almost happened to someone else [..]"* (lines 1329-30). He is not sure what can make the difference, but sometimes he can perhaps feel as though he has distanced himself to the point that he feels he is talking about something that happened to someone else. This is noteworthy; during my analysis of Vivienne's transcripts, I perceived that he talked about different aspects of the experience from different perspectives. For example, Vivienne's account is the most 'rehearsed' compared to other accounts which are quite 'naïve', as he has done the most publicity work around CO; this persona reflecting his awareness-raising activities became an emergent theme that was entitled 'the renowned'. The discomfort and reluctance he feels on occasion is outweighed by the *"greater good"* (line 3073) which is the benefit of raising awareness. For the sake of gaining a wider reach, for example, he has given an interview to a "*horrible, <u>horrible</u> paper"* (line 1056); although he says that the journalist who interviewed him was very good, *"but, ah god, it's cheesy [.] but, em, as I say it's important" [.]* (line 1061). However, he is clear that his campaigning work is solely for the pragmatic purposes of raising awareness about the dangers of CO exposure, and does not serve another, more 'inspirational' principle. For Vivienne, his loss is not ameliorated by the work that he does:

> *I don't really like the expression that erm it gives, you know someone who has died in a particular accident and you do general things about it, like gathering money or awareness or raising awareness, that that gives that death, meaning [..] no it doesn't, to be perfectly honest, em, I would much rather have [name of partner] back and never have heard of carbon monoxide* (Vivienne, lines 1272-7)

## **<u>Connectedness</u>**

Unity and social cohesion are important for human survival; people feel a connectedness to each other and have affinity for each other's suffering. Vivienne recalled one occasion when he became upset while talking to a radio journalist. This interview was one he knew to be instantly impactful and which therefore had served its purpose, as someone he spoke to later that same day recognised his voice and revealed that the interview had made him immediately purchase a CO alarm. This man had recognised his connectedness to Vivienne and appreciated that he and his loved ones would be safer by making such a purchase. Vivienne recalls the interview, where the host of the show allowed him to talk about the experience in his own way:

> *She was getting very very emotional … em, so, but, because of [.] I think, I mean it was extremely effective, because, her, getting affected by it, almost affected the people more than, the story in the first place, I would say, I mean, I find this, as well [..] I get almost sadder if I see someone else being sad* (Vivienne, lines 1510-4)

Vivienne feels that it became more difficult for him to talk about what had happened, because it was difficult for the radio host, although she was a stranger to him, to hear his account and think about all that he had endured. This is strongly linked to the preceding raising awareness theme; as has been seen, the connectedness that the participants themselves have with others provides motivation to campaign so that all of us can benefit from increased awareness of the issues around CO. This selflessness takes many forms throughout the participants' accounts.

All participants in this group talked about some form of altruism and connectedness. Interviewing Tisha and Ajay together was interesting from this perspective, as they share a deep connection. Ajay feels that his motivation to help Tisha stemmed from their love and connectedness and the connection that existed in their extended family. This connectedness helped him on the morning when the CO was discovered. Tisha was talking to her mother on the phone in the living room, too weak to move or call out to him, Ajay, in the next room, so her father had phoned Ajay:

> *It's having that family support it's like if her Dad didn't ring me, I wouldn't have got up, and I was in no state to call out, so, and the second day, you know it's very scary, because when you [..] the only real time I felt comfort was when I was lying in bed, just resting, and that's obviously the worst thing you can do* (Ajay, line 716-9)

The dyad were desperately ill and deteriorating quickly; they were both so ill they were essentially trapped in their flat while the levels of CO continued to rise, as they couldn't get to the front door to open it for the paramedics. Having only moved in a few weeks before, there were not any neighbours *"that we knew of that well"* (Tisha, line 162) to help them. Fortunately, Ajay *"just about"* (line 168) managed to open their front door. He later reflects on how he found the strength to do so, saying that he perceived that this was:

> *Because we love each other that [.] and also newly married so you'd do anything for your new, wife husband* (Ajay, line 736)

Ajay also discussed concerns about his potential cardiac issues which were observed as a result of the CO exposure, finding the experience was *"very upsetting"* because *"obviously to have that would have inflicted the family a lot of pain"* (line 1425); his first thoughts were of the people he is closest to, rather than himself. Tisha talked about an instance that showed altruism and connectedness from people she did not, at that time, know very well rather than family or close friends. She had recently started a new job and had to tell her employer what had happened, apologising for her absence from work as she did so. His response:

> *He was utterly speechless … he said, you almost just lost your life, and I just want you to get better, and recover [.] you know, and they sent me some flowers and I had people come to see me, and I didn't, I barely knew these people, I knew them for about four days, so, you know, the support that I got from them and are still getting from them, has just been absolutely incredible* (Tisha, lines 379-83)

Matt stands out as an exception to this theme, in that he talked about connectedness in general and to his family in particular that he now experiences as an absence, not a presence; he remembers that connectedness was, until the CO exposure, something he felt through emotional responses. For instance, speaking of bereavement, Matt feels that his responses to others' deaths have changed, and that his current response is difficult to comprehend even for himself:

> *Somebody quite close to me has died, it's not [.] it's sad, but, I don't [.] dwell on it, it's [.] … I don't go any further than really feel, that's very sad, you know, but, I don't, don't think about it after, which is, strange, which is, you know, when I think about it after, when I've seen people so upset, and it goes on and on, you know, and I don't get like that, either, so, I don't, it's a matter of fact, and that's happened and that's it* (Matt, lines 221-5)

Although he is aware that other people respond differently, that now does not perhaps feel like a usual response to him. Others' grief can go *"on and on"* but never, at any point, seems to impact on him, even though he appreciates almost as an abstract that death is sad. Daisy was helpful in clarifying the effect this had on family life, and how big a change it was. Her comment is shown here as it sheds much light onto Matt's perspective:

> *He used to be quite empathetic but he's not now [.] … and he's- you're not as emotional, are you? … Like, if somebody's upset, I don't, really think he gets it … I've noticed that, [name of daughter]'s noticed that* (Daisy, lines 3307-13)

In his response to this comment, Matt again stated his awareness of the disparity, but did not seem to wholly manage to address the issue that Daisy was talking about; his lack of emotional reaction blunted his reply to a focus on the practical, instead:

> *I'm mean I'm aware of that, you know, I only, it's not that I don't care, you know, I do, and er, I do everything to er, to help, don't I? With the girls and that, you know, [name of daughter] and everything* (Matt, lines 3314-6)

Bookie felt a sense of connectedness with a community he had never met. He likened his own court case to the Hillsborough enquiry, perhaps seeing similarities in another 'David and Goliath' situation; one person facing seemingly insurmountable odds against a vast and complex adversary:

> *I thought of them I thought, you can't bring them people back you can't allow them to carry on with their lives, and all that, but when I see, all the injustice, and all the cover-up and all the rubbish - you know what they've been through, which is similar, they've gone through far [..] since what 1989, I remember when it was happening, they've gone through that, and I'm moaning about going through it for four years [.]* (Bookie, lines 457-61)

Even in this comparison, Bookie seems conscious that he does not want to diminish anyone else's suffering by contrasting it with his own, which he feels is less than theirs. Bookie's motivation for participating in the study was partly driven by this altruistic inclination *"if it helps somebody else, because somebody else in this situation might just think it's them [..]"* (line 1041).

## Summary

In this chapter, I have presented findings from group one. I have conveyed the effects of the traumatic experience that is exposure to CO, including issues of bereavement, traumatic effect and power and justice. I have also explored ideas presented by the participants around identity and connectedness. In the next chapter, I present the findings from group two.

# Chapter seven: Findings from group two

# Introduction

In this chapter I present the findings from group two. The exposure that this group experienced lasted for months or years. Due to the exposure most likely being of lower concentrations of CO, the participants' symptoms did not result in a timely clinical diagnosis of CO exposure, despite consultations with various healthcare professionals, notably GPs, A&E department staff, and hospital consultants, as the exposure caused a wide variation of symptoms in this group. The same key themes of 'traumatic experience', 'power, justice and judgement', and 'identity and connectedness' are presented here with the addition of a further superordinate theme, 'everybody seems to be in the dark', which refers to the difficulties faced by this group in recognising that their symptoms were caused by CO exposure. Table ) shows participant representation in each of these themes. Some overlap between themes is evident in their presentation. This group are Curstaidh, Kate, Be, Lizzie, Sarah, and Showgirl. Again, please see the pen portraits (appendices 1-12) and tables 2 and 3 (appendices 12-13).

## Table 12: findings from group two showing participants' representation in themes

| Superordinate themes: | Subthemes: | Curstaidh | Kate | Be | Lizzie | Sarah | Showgirl |
|---|---|---|---|---|---|---|---|
| **Traumatic experience** | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Power, justice and judgement** | Invisible woman/*"crazy lady"* (Sarah, line 2203) | | | | ✓ | ✓ | ✓ |
| | Moral judgement and gender | | | ✓ | ✓ | ✓ | |
| | *"No such thing as justice"* (Bookie, line 453) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Identity and connectedness** | The struggle to maintain identity following exposure | | ✓ | ✓ | | ✓ | ✓ |
| | Raising awareness | | ✓ | ✓ | | | |
| | Connectedness | | ✓ | ✓ | ✓ | ✓ | |
| **Everybody seems to be in the dark** | *"I couldn't put my finger on it"* (Kate, line 196) | | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Ignorance and wilful ignorance | ✓ | ✓ | | ✓ | ✓ | |
| | Revelation | ✓ | ✓ | | | ✓ | |
| | *"Carbon monoxide does not exist"* (Be, line 3757) | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| | Other agencies and ignorance of CO | ✓ | | ✓ | | ✓ | ✓ |

## Superordinate theme one: traumatic experience

The realisation that they had been exposed to CO constitutes a traumatic experience for the participants, which had an impact. One of the immediate concerns was, perhaps, dying from the exposure. Be felt extremely ill on several occasions, and explicitly thought she was going to die during an A&E admittance:

> *I really thought I was dying, I thought I'm not going to make it through this, I said, I said I really want to see my children grow up, please get me, please give me some oxygen, I can't breathe* (Be, lines 563-4)

Whilst relating this part of her account, Be was extremely emotional, as she recalled her fear and desperation. Talking about the impact of this incident later, she couched death in more implicit terms, perhaps as an inescapable event in which her existence could be simply snuffed out as the situation overwhelmed her: *"yeah so thinking that the big 'pouff' was going to come, I was just terrified"* (Be, line 2992).

Be's exposure was protracted and her experience is characterised by the traumatic effect of having to fight to be heard as a consequence. She also used another powerful image to express the combative nature of her experience: *"it's not by coincidence that they use gas [.] in warfare [.] there is a reason for it"* (Be, line 1516). This expresses the horrific, devastating circumstances in which Be found herself. Gas use in warfare demoralises and harasses the 'enemy' and causes panic and anxiety, in addition to its debilitating, indiscriminate physical effects. It's a powerful symbol which likens the experience of being exposed to CO to being devastated by war, and which weaponises CO.

Showgirl also mentions death as the potential conclusion of her situation. This quote demonstrates her frustration over not being listened to or believed by the Environmental Health Officer who came to investigate her concerns. The quote was made in the context of the lack of understanding about CO, but belongs here as Showgirl was telling me how worried she was that she was going to die from the exposure. She knew there was a serious problem, but could not compel someone who should be helping her to see that:

> *I said to the environmental health person ... em, you know I said, what do I need to do, do I need to die? Is that what I need to do? Because, would you believe me then, when I'm dead […] or will they put that down to something else? Because that happens, doesn't it?* (Showgirl, lines 760-3)

Curstaidh, Kate, Be and Lizzie shared their homes with their children at the time of their exposure, so their fear was compounded by the effects that they perceived were being caused by CO exposure to their children. Lizzie, too, alludes to the possibility of death, and also raises the issue of parental responsibility:

> *Oh, it was a terrible time, I really felt [..] it-it [.] it was just like, oh shit [.] oh shit [.] it looks very much to me here like I'm not going to get out [.] and my god, my kids [.] I can't get out, no matter how much, I can't [..] raising the alarm is not working [.] there is nothing [.] that I can do? This was [.] and I suppose that, I suppose there was an element of it, doom laden, about this, too, aye (sighs) it was a dreadful time [..]* (Lizzie, lines 653-6)

This quote shows how desperate the situation was; Lizzie feared that she might lose her life and was consequently afraid for her children. She felt trapped and panicky, shown through the repetition of *"oh shit*" and *"get out"* and *"oh my god"* as well as the pauses she makes in this situation. She had tried hard to alleviate it in some way with no result.

Lizzie explicitly described feeling guilty that her children, then aged eight and two, were exposed to CO: *"I feel a lot of guilt as well, you know? If I had tried harder, to raise the alarm, but I couldn't have [.] you know, there was <u>no more</u> that I could do […]"* (Lizzie, lines 660-1). She rationalises that she was doing all that she could to alert people to the plight of her family, but that she perceived that she could not make a difference as she was not listened to throughout this time. Looking back on the period of exposure, Curstaidh also states:

> *But it was qu- a very frightening experience, and certainly as a mother, thinking that I had put him [.] inadvertently, in a position where [..] it could have affected his long-term health, it could have been worse than that and that's, very [..] very distressing, to think of that with my son [..]* (Curstaidh, lines 135-8)

Although Curstaidh doesn't mention death or dying explicitly, in this quote she alludes to it by saying that the situation could *"have been worse"* than affecting her son's health. She is here also talking about the responsibility that all parents feel for their children at all times, but perhaps especially in difficult situations; ultimately, she feels responsible for his health, wellbeing and life, and she expresses distress that she perceives that she has, albeit completely unintentionally, put his life in danger.

Kate also talked about the impact of the exposure on her mood, saying that the depression she developed brought her so low that she was actively contemplating suicide, unbeknownst to even those closest to her. This, she felt, was a complete change for her:

> *I ended up, with depression [.] now, my personality isn't [.] naturally, I'm not, a depressive person, I'm quite positive, and upbeat, and [.] all of a sudden I just felt horrendous, and I had that for 18 months, er, to the point where, I used to [..] I used to walk up to the bridge and look over there and I don't know if I want to jump [.] so I used to walk up every day with the dogs and look over, … that's what I was contemplating [..] nobody ever knew this, even my husband didn't know this, so [.] it was a big [...] but it did affect me, it affected me, you know, in a big way […]* (Kate, lines 381-8)

Although she didn't usually consider herself as a person who could suffer from depression, Kate here related that the traumatic experience of the CO exposure and aftermath was so devastating that it rendered her with suicidal thoughts that lasted for a considerable length of time. Her very existence, under this overwhelming feeling, caused her considerable and painful anguish. Her previous persona could cope with life's ordinary happenings, being *"positive, and upbeat"*, but this persona was defeated. She suffered with this without talking to anyone about it; perhaps her feelings of despair were just too great.

Kate has many sequelae to contend with; the most considerable for her is that she lost the cognitive ability to read. This form of agnosia is termed alexia; for Kate, this was a particularly burdensome and traumatic element of her experience: *"that was the worst, that must have been the worst thing of everything"* (lines 1106-7).

Sarah suggested that she had thoughts of a similar vein, but with some subtle variance. She felt that her quality of life became very poor during her long period of CO exposure. She alluded to *"it not being worth it"* (line 1180) during her first interview. This was something I later encouraged her to revisit. Her suffering was so extreme during this time that her thoughts reveal how low she became and how she considered ending her life. She talks about this in a seemingly rather factual, down-to-earth way, having had no misgivings at the time around thinking about ending her life, since the process of trying to maintain her 'normal' life was exhausting and unbearable. Without explicitly mentioning the word itself, a form of suicide seemed almost rational for her:

> *It felt like [.] you know [.] the idea was of [.] euthanasia, you know? ... Just like, somebody who's got a really bad illness who knows they're dying anyway [..] and they just kind of go oh I'm choosing I don't want to get any worse than this, you know, really this is my time I've had enough, that's kind of like what it was veering towards, that's what it felt like it was going towards, and it was just starting to become something that I was thinking about, like [.] there may come a time when that's really what it is, you know? It really did feel like, it wouldn't have, it wasn't like, it didn't feel like a, suicidal thing it wasn't, I can't take the world anymore! It was just like [..] you know, there's <u>no</u> quality of life* (Sarah, lines 3385-92)

Euthanasia is usually the termination of someone's life when they already have an incurable condition. It relieves intractable pain and suffering voluntarily, when the person's life becomes too burdensome for them. Euthanasia did not seem to be a 'dramatic' issue for Sarah, she was almost resigned: *"this is my time".* Her use of the third person here may indicate that she wants to put some distance between herself and the traumatic thoughts that she had. Inserting a neutral *"somebody"* and speaking of this in the past tense perhaps makes this revelation slightly less personal and situates it further away from the thoughts that she has now as she slowly recovers.

Be's traumatic experience, during which she and her family were exposed to CO for the longest time out of the whole group, is summarised here, when she talks about how violated and devastated she feels:

> *It sounds horrible to say this but I feel like my life has been raped and I think to myself [..] it's like calling in [..] so, you have your boiler maintained by somebody, erm [.] and it's like calling in the rapist to come and investigate, so the very people who have been causing the problem, it's calling them back into investigate [..] so you have an emergency service that comes in and says yes there could be a problem [..] right, let's call the rapist back in to come and investigate it- that's what it feels like [..] so you stand <u>no</u> chance in <u>hell</u> [..]* (Be, lines 2900-05)

Although she finally gained some recognition of the problem, the support she received felt like a further violation. Societal discussions about rape, which are beyond the scope of this research, can use a lexicon of victim blaming (for example, was the victim drunk? What was the victim wearing?) while perpetrators are often not reported, caught or punished for their crimes. This fits with the way Be feels she was treated over the period of the family's exposure; she felt belittled and disregarded, and blamed for the family's problems herself (see discussion below about moral judgement). This striking imagery is Be's way of conveying just how total the damage to both her life and her family's life was, and how inadequate she was made to feel in trying to address any aspect of the situation.

## Superordinate theme two: Power, justice and judgement

This theme concerns the power relationships that were encountered during the course of the exposure itself and in its aftermath. The subthemes here are 'invisible woman/*"crazy lady"*, moral judgement and gender' and 'no such thing as justice'. Often, participants were seemingly frustrated by their powerlessness in the face of the effects of the exposure and by the actions of others with regard to the experience. Be (line 2018) and Lizzie (lines 160 and 683) talked about being at a *"dead end"* either when trying to seek help or in terms of being offered misdiagnoses. This theme therefore covers this sense of being stuck, with no help forthcoming; of being frustrated as a result of not having a voice when more powerful people (such as healthcare professionals) would not support them.

### Invisible woman/*"Crazy lady"* (Sarah, line 2203)

Power relations are implicit throughout this section. Participants tried to gain support and understanding from others around them, but were frustrated in some instances by the power dynamic between, for instance, doctor and patient. For the women participants who did not have immediate recognition that they were suffering the effects of CO exposure, issues around power between themselves and the agencies from whom they sought help, or were involved in their accounts, often focused on gender issues.

The issue of gender is an important part of Showgirl's effort to be heard by all around her. She perhaps fears being judged as a *"crazy woman"* (line 631). This is a persistent trope which means that women are not always listened to, or don't always have their accounts taken as seriously as men's, since women are seen to be less likely to be 'rational' and more likely to be 'unstable' than men. The term 'crazy' can easily be equated with some sort of mental incompetence, instability or insanity. If a woman is 'crazy', then perhaps by default the person, regardless of gender, calling her so is juxtaposed as being sane, and 'not crazy'. Sarah uses the term in the context of being seen as *"just some crazy lady who uses the internet too much"* (line 2203) by her male consultant; this lens would deem her to be not sensible or capable of understanding what her symptoms meant, or of exaggerating and panicking unnecessarily, and that she should be condemned for those things. Showgirl also uses the term when trying to explain her situation to her friend. Not being *"crazy"* in this context would mean that she was indeed suffering from something beyond her friend's comprehension; if she was, however, a *"crazy woman"*, it would just mean that there was nothing really wrong with her, and that any issues were fabricated:

> *I'm not ment- I'm not crazy, you know, I'm not a crazy woman, this, is happening, I don't, I can't explain it all, but [.] it's happening, and, you know, and that's why I couldn't get my head round because I was like, you* <u>*know*</u> *me though?* (Showgirl, lines 631-3)

Showgirl may have stopped herself from saying *"mental"* here, as it has become a pejorative term for people suffering from mental health disorders and is suggestive of stigma. It could also be considered to mean or suggest that someone is acting in a way to provoke laughter or in a silly, stupid manner. Showgirl is neither of these things; rather, her CO exposure meant that things were happening that were not easy to explain.

For Sarah, as a professional, educated person, it was disheartening to be treated in a *"patronising and disrespectful"* (line 91) way by her consultant, who seemed to assume that she was mistaken about her own symptoms or knowledge about her underlying condition. She felt that her condition may be worsening during the time she was unknowingly being exposed to CO. The consultant certainly seems to have disregarded her input, despite her bringing her previous records about this condition from another consultant; she perceived a patronising attitude from him initially, but he then became *"aggressive"* (line 1012) and reproached her for contradicting him. Following the consultation, he wrote letters for her medical records that say: *"there is nothing physically wrong with this woman"* (line 85), suggesting perhaps that if she continued to complain of symptoms, their cause was psychological. He also accused her of gaining information from unreliable, internet sources, and referred to her as *"this lady"*. Although his older age means that his use of the word may have been simply automatic, the use of the term 'lady', when not juxtaposed with the term 'gentleman', does not merely imply a female adult. It can, rather, subtly uphold antiquated ideas of femininity and gender, and suggests here that as a 'lady' Sarah was incapable of understanding her underlying condition and negotiating her health care with him, and even, perhaps, overstepping the boundaries of behaviour of what would be expected of her as a 'lady':

> *Cos that asshole who wrote those letters about this lady reads the internet too much, I was trying to engage with him, I had plenty of information and understanding and knowledge on my condition, and that made him more determined, to tell me that I was wrong, based on no information!* (Sarah, lines 996-8)

In Sarah's experience, gender is key, and she perceives that *"as a woman"* (line 715) she is not taken as seriously and does not have the same voice or power that a man would in the same position. Sarah was fervent, showing her anger and frustration, as illustrated by her tone and emphasis here:

> *Yeah, no, there's been no respect, there's been no like, oh well, you're an intelligent person, you know, so you're probably like, someone I should take seriously [.] not a chance! But then again [.] as a woman I have never found doctors or GPs to be particularly respectful, my consultant in [place] is a woman [..] she's grand [..] she treats me like an intelligent equal [..]* (Sarah, 713-7)

By pointing out that she is treated as an *"intelligent equal"* in some circumstances, Sarah shows that the opposite is true of another consultant. Sarah's experience seems to demonstrate that her female consultant was far more willing to work with her. Her experience of repeatedly going to her (male) GPs to report the fatigue that was the defining and most burdensome symptom of her CO exposure, and then not being heard or even believed, has led to a firm consolidation of her views on them:

> *I'd already kind of seen that, I'd already seen male GPs just go I don't wanna hear about it that you're tired, I'm gonna decide that there's nothing wrong with you, and in my [..] amazing wisdom, I'm going to be right, because I said so, and so I was just like, oh fuck you again, you know?* (Sarah, lines 2001-4)

In response to my seeking further clarification on her perception of her views being contested, even by people who are supposed to be experts, Sarah stated that she did find it frustrating, and even though we had not specifically been talking about gender immediately before that, her response was:

> *It is frustrating, it is, and yet, to be honest, men being idiots is not a new thing you know, it's, it's always frustrating* (Sarah, lines 3189-90)

Lizzie's husband did not want to hear about the effects of CO exposure and would try to discredit Lizzie by manipulating their young children into teasing her about it. Many years later, the recounting of this incident was still very distressing to Lizzie:

> *L: he thought, I was ridiculous going on about carbon monoxide … so he had the children chanting, "carbon monoxide, carbon monoxide" […]*
>
> *J: oh [..] that's just [.]*
>
> *L: it's your crazy mother* (Lizzie, lines 874-80)

Lizzie confided that her husband had been speaking to her doctors behind her back and that the doctors had listened to him, perhaps perceiving him as the dominant man, rather than working with her, the less influential woman. She felt dreadfully powerless: *"just because, the man has spoken, the man of the house has spoken"* (Lizzie, line 611). Male family members who are the *"man of the house"* take responsibility and make decisions for the rest of the household, who are positioned as being weaker than they. This positions the 'man' as the most important person, and Lizzie as having far less power due to her gender and status as his wife. As she already had a label of the psychosomatic disorder Functional Neurological Disorder, Lizzie felt that any healthcare professional would not take her concerns seriously; she expresses this in gendered terms, and found recounting this experience upsetting: *"ignore this woman […] silly woman"* (Lizzie, lines 644).

*"Silly*", especially, portrays a lacking in sense, a stupidity, and a weakness of mind. It can be used to describe people who are immature, impulsive and emotional, and lacking depth of character. In fact, when being investigated for a condition that was more concrete, in that it was a purely physical/physiological infection, Lizzie still expected to be handled in the same way, and uses the term *'crazy'* as a noun rather than an adjective to inform me of just how she expected that encounter to proceed. She was astonished that it differed from other interactions:

> *I was taken seriously and that threw me sideways because I, really expected, you know, to be dismissed again, and treated like a crazy, but that was all very straightforward* (Lizzie, lines 706-7)

## Moral judgement and gender

Ideas around power and gender are linked closely to the concept of moral judgement that formed part of some participants' accounts; in addition to perceiving that their accounts were not being listened to or believed, some participants encountered a judgement of their accounts and/or actions. Speaking of her encounter with the male consultant, for example, Sarah deplores the way she was spoken to and uses a term that can reference the stigma of mental health to convey her frustration:

> *No-one should speak to anybody this way, even if I was, a lunatic, you still shouldn't speak to me that way! [..] You know, apart from the fact that I'm not a lunatic and I'm making reasonable points, you shouldn't speak to anybody that way!* (Sarah, lines 1023-25)

Sarah is making the point that she is aware that such a negative and dismissive attitude is neither warranted nor helpful under any circumstances. Someone who presents with symptoms, but without physiological evidence of an illness, such as those that can be found in common investigations, still may well be ill. Someone with a mental illness is also, of course, ill.

Be feels she was *"accused"* (line 754) of having Munchausen's Syndrome by Proxy (MSBP), now known in the UK as Fabricated or Induced Illness (FII). She found this to be terrifying, meaning it stopped her seeking help from her GPs, despite how desperately worried she was:

> *Yeah [..] that's how I felt, and the fact that they- not only mentioned [..] that, that we think you've got Munchausen's, but actually backed it up by saying [.] using, referring to Social Services [..] that left me terrified [.] and the effect was I stopped going back [...] erm now, yeah it was just [...] and I did I felt accused [..] and that continued, I did just felt accused, the whole way through [.] not only do you have Munchausen's you have now [..] drawn your family down* (Be, lines 3880-5)

This accusation and concomitant perceived moral judgement of Be had some difficult consequences for her. She felt she was under scrutiny, mistrusted and unable to access any support, whilst watching her own and her family's health continue to decline. When Be was aware of the CO exposure but still unable to convince healthcare professionals, she had requested a blood test for her children to try to establish the presence of CO. Unbeknownst to her, she had asked for an arterial blood gas, not realising that carboxyhaemoglobin can be measured through a less painful venous blood sample. This request was denied, but a paramedic, on being called to attend to one of the children, said:

> *What kind of mother are you, who would put her children through painful blood tests for, for no reason at all? [..] That's what she said to me, yeah I will never forget it* (Be, lines 1989-92).

The paramedic is quick to shun Be for her behaviour here; the *"for no reason at all"* signifies that Be's protestations about CO exposure were not taken seriously. She *"raised the alarm"* (line 1977) but was not given the test which could have substantiated her claims.

Be recalls clearly how painful it was to be thought of in this way, as a danger to her own children, a memory which still causes her distress:

> *When you're judged as though you would hurt your own children [..] I think, that's what I carry deep in my heart [..] because I would give my life for my children [..] and for them to have put those, thoughts into their hearts [..] that I would harm them [..]* (Be, lines 3147-50)

Lizzie was also seemingly very cognisant of the effect of being labelled with a condition that was deemed to be psychosomatic, although she did not state it in the same explicit way, and terms such as 'Munchausen's' or 'fabricated' were never used. She perceived that this labelling meant that others, including her then husband, thought her symptoms either had a psychological basis, or that she was fabricating them; that they did not have a physical basis as such a basis had not been found in the physiological investigations conducted by healthcare professionals. In this quote, she appreciates that others could perceive this to mean that her children were in danger, and again, she is quite clear that culpability has been attempted to be apportioned to her for the situation:

> *I mean, you know, there was what was wrong with me, but, why would I be doing that to my children? […] Really? You know, you cannot place the blame for that on me, I would never [..] hurt my children, and they were clearly not well […]* (Lizzie, lines 259-61).

Both Lizzie and Be were aghast when recounting this suggestion. While these mothers of sick children were seeking help for their families, healthcare professionals had considered the possibility that they were exhibiting the opposite behaviour – causing harm to their own children by exaggerating or even causing symptoms due to their own psychological illnesses; their continued requests for help and support were seen as further signs of this illness. This line of thinking is connected to the idea of insidious or elusive CO. As symptoms were often non-specific, or had improved by the time a child was seen by the healthcare professional, as they were away from the source of exposure (which could be taken to mean that the mother *was* exaggerating), it can be seen that healthcare professionals might have considered a fabricated disorder as a cause of symptoms because they did not consider the possibility of an environmental cause.

## *"No such thing as justice"* (Bookie, line 453)

Be is now focused on justice and feels that her anger over her situation has motivated her to seek justice and campaign with charitable organisations and so raise awareness about CO. For Be, these actions perhaps give meaning to her experience. The 'they' to whom she refers in this context are healthcare professionals and Social Services:

> *My main focus is my children but also, just to give meaning to, to my struggle, my life, hope that people learn something from it, erm, and most of all to hold these people accountable [.] because, they, they cannot railroad people's lives like this and think that they can just get away with it [.] erm, and yeah, no [..] so it's given me a resolve, em, in talking more about it and, I think it's such a huge big issue* (Be, lines 4381-87)

Participants continued to try different and diverse avenues for tackling this complex situation. Be's quote alludes to justice, as part of her motivation for campaigning is to *"hold these people accountable"*. Other participants also talked about striving for some form of justice. These actions may have reflected on participants' desire to maintain their own identities and sense of self, by finding and making meaning through their experiences, despite the negative outcomes and responses with which they were dealing. These concepts are presented here.

The notion of justice as the administration of the law in maintaining fairness applies to some of group two. Curstaidh also sought the advice of a solicitor, due her landlord's failure to fix the source of the CO exposure and the subsequent problems she faced with him. She was encouraged in this by the CO charity with which she engaged, as it would be *"for the sake of other people"* (line 440), again perhaps helping to avoid a similar situation for any other family who found themselves renting from a rogue landlord. While the endeavour proved unsuccessful, she was clear in pointing out that her motivation for trying to sue the landlord was not monetary, but to set the situation to rights: *"it was never about money anyway, it was about [..] he was <u>wrong</u> [..] and he should not have rented out a property that failed on so many different levels"* (Curstaidh, lines 330-2). In this way, she was perhaps positioning herself not as someone who was the hapless victim of a powerful landlord, but as someone who was strong enough to seek justice, so that others would not be so vulnerable if they encountered a similar situation.

A further source of frustration and powerlessness was found in various assumptions that were made. Showgirl did not want to take her neighbour, who was burning rubbish in his fireplace, causing CO to travel through his faulty chimney to Showgirl's house, to court, although the Environmental Health Officer appeared to think that that was the rationale behind her complaint. She had to clarify that she just wanted the neighbour to stop the behaviour that was causing the CO exposure:

> *It was oh well we've got to, have some evidence? … You know [.] before we can prosecute, I said I don't want to prosecute, it's not my intention [.] it's not what I want [.] … I said to them*

> *I don't know, what, what kind of … people you normally deal with, … but [.] I'm not, one of those people, I don't want that, I just want this to be sorted out* (Showgirl, lines 1127-33)

Showgirl here seemingly defines herself as another sort of person with a different outlook from the people that the Environmental Health Officer *"normally*" comes into contact with; she is not someone who wants to prosecute someone else, whether for compensation or to see justice done, she is someone who wants support in sorting out a difficult situation.

At the time of her interviews, Sarah was trying to find a way to seek justice and recompense from the housing agency who were responsible for organising the gas safety checks as well as the company who carried out the checks. She talked about compensation for her ordeal, and pointed out that what she really wants:

> *Is, for it not to be something like they act like it's just ok, like it's no big deal, and the HSE … we're going to take it forward as no-one was hurt [.] and I was like, well, I was hurt, I was really sick … and, they were like, well that's not how we classify things [..] and I was just like well fuck you guys [..] it was like oh someone could have died and that's terrible but they didn't, so that's ok and actually three years of my life were really kind of fucked up, oh no, we don't really care about that, that doesn't count [..]* (Sarah, lines 906-11)

Justice is an important concept for Sarah, as the perceived and rather flippant indifference towards her exposure to CO feels inappropriate to her; her frustration and anger that her ordeal is not to be acknowledged is clear in this statement through repeating that she was *"hurt*" and for her, the situation is indeed a *"big deal*", regardless of the Health and Safety Executive's position. Her swearing shows her anger and contempt for this decision. If CO exposure does not prove to be lethal, it seems that the injuries and issues that exposure brings can be disregarded.

Sarah described a discussion with the independent engineer she contacted to assess her particular situation:

> *He … didn't say it outright, but he was kind of saying (whispers) this is never going to go anywhere like he was saying this isn't go to go anywhere, he didn't say it like that, but he was very much like, I can't give you any advice, but he was clearly very much, in that, legally sensitive frame of mind, but he was just like, this isn't going to go anywhere [..]* (Sarah, lines 408-12)

Her description alludes to a secretive, perhaps conspiratorial feeling, where the engineer whispers and repeats that he did not think that her case would *"go anywhere*", as it was not 'serious' enough. Sarah feels both powerless to counteract this position, and that it is unlikely that she will receive justice for her experience.

Kate, like Bookie, was successful in bringing those responsible for her exposure to formal justice; however, this process remains unsatisfactory for her. The family were awarded money as the building company admitted negligence. They did not admit, however, to causing the problems that Kate and her son continue to experience, saying that those problems could not be directly linked to CO exposure; there is a lack of scientific evidence between exposure to lower levels of CO over a long period and the origin and progression of the conditions with which Kate and her son continue to suffer. Although she was also not motivated by money, Kate feels that the sum they were awarded was *"nominal"* (line 457) and *"laughable"* (line 1341), and in no way afforded them true justice. They continue to experience substantial and ongoing problems, which she firmly perceives as being due to their exposure and which the justice process could not recognise:

> *The severity of what happened wasn't really, wasn't really taken into consideration [.] and then again settling, so early, when you don't know what's going to- how your life's going to pan out and how it affects you, and same with [name of son] [..] you just never know* (Kate, lines 1344-6)

Kate settled out of court. The justice system could not recognise their ongoing problems as the evidence base around CO exposure, especially at lower concentrations over a prolonged period, is not rigorous enough for the courts to determine that a negligent action caused all of the family's symptoms and sequelae:

> *They wouldn't admit causation … because what else would would change your cognitive function from, as in a mental level which he was accepted into Mensa at that age, at six, and then, three years later [.] you're below average on everything … so, well what else could it have been?* (Kate, lines 1323-8)

Lizzie realised she wouldn’t be able to seek recompense through the courts, even though it seems as though the first engineer to service the fire had been negligent, as he had passed the gas fire as ‘safe’ without comment:

> *L: […] (long pause; very emotional/tearful) [..] yeah so, I’m, I kind of, for a wee while thought I’m suing [name of gas provider] because we’ve had a three-star contract here, and the guy before, the guy the first year, could have, discovered that,*
>
> *J: yeah,*
>
> *L: […] erm [..] so, you know, I was quite keen to er [..] sue, but after he’d gone, and I looked at all the, er […..] paperwork from the sale and all that, it actually says on it [..]*
>
> *J: does it?*
>
> *L: yeah, it says on the survey [..]* (Lizzie, lines 880-6)

The house survey indicated the presence of the debris which caused Lizzie’s CO exposure. Lizzie thinks her husband didn’t want to be reminded of CO as it turned out he had had access to knowledge which could have meant the situation was avoided entirely:

Lizzie’s husband had had sole access to the house survey results, which stated that the chimney (to which the gas fire was attached) was thoroughly blocked by building debris, dating to work that had been done before they had moved into the house. It could be that the report was not explicit enough – its author had not stated explicitly that the fire needed to be condemned. This is, of course, speculation; what is clear is how Lizzie experienced her husband’s persistent reaction to the mention of CO as *“angry”, “aggressive”* (repeated) and *“nasty”* (also repeated). Lizzie had not seen the survey papers before they had moved in, and therefore could not know herself of the danger that using the gas fire posed. The first engineer, however, had had the opportunity to save them a year of further expose and concomitant health decline, but did not. The presence of the survey results meant that any sort of retribution for his omission would probably not be forthcoming.

## Superordinate theme three: Identity and connectedness

This theme details issues which affected participants' identities or sense of self. This was important to the participants, who reflected that the traumatising experience of CO exposure had been disruptive and led to some fragmentation of their sense of self. The motivation for participants to campaign with charitable organisations and engage with the media to disseminate the message about CO will also be discussed in this section, as this supports and illuminates important ideas of connectedness with regards to participants' experiences of CO exposure. A sense of connectedness and fellow-feeling supported participants and allowed them to feel that something positive can be derived from their trauma. This will be presented through the subthemes 'the struggle to maintain identity following exposure', 'raising awareness' and 'connectedness'.

### The struggle to maintain identity following exposure

Participants were frank in discussing the effects of their experiences of CO exposure in terms of their fundamental core and sense of self. The ongoing nature of the complexities and difficulties of being exposed to CO and then attempting to resolve situations that were caused by that exposure were extremely taxing and had profound implications that included threats to self-image. Initially, participants noticed that the affective and psychological symptoms of CO exposure conflicted with their usual personalities.

CO exposure wrought changes that left Showgirl with the strong sensation that at times she was no longer her 'real self'; she felt *"like, not myself at all"* (line 1032); she was *"fidgety, and, erm, I was a bit irritable, a bit, cross, erm [..] you know, just felt really, unsettled, and that isn't me at all, that's the opposite of me [.]"* (lines 1011-2). Her 'real self' is none of those things; the CO exposure is perhaps causing that 'real self' to crumble.

Kate identified herself as *"positive, and upbeat"* (line 382) before the exposure. She reported feeling taken aback when diagnosed with severe depression after her exposure was discovered and is, here, adamant that this would not have happened if not for the CO exposure. *"As I say I never had any history of it, my personality [.] erm, if somebody said to me, you'll have depression over it, no [.]"* (lines 397-8).

Kate's agnosia alexia had a considerable impact on her sense of self. Losing the ability to read and being forcibly changed from being an *"avid reader"* (line 1103) signified substantial change for how she perceived herself:

> *It's gone, you know, how you gone from somebody who can, you know, read, write [.] you know, I went to uni, did all that and then all of a sudden I can't read now [.] so that was that was, that was probably one of the worst things actually, the reading thing really affected me* (Kate, lines 1468-70)

Kate identified herself as capable and enthusiastic about something as commonplace and necessary as reading, and now has to amend that aspect of herself. She became someone who, quite abruptly, could not read. She remained stoical and taught herself to read again through determination and perseverance. She seems to have shown great strength and resilience in coping with her new life; she also now appears to identify as someone with the limitations of a brain injury, without knowing how much damage has been done and how she will be affected in later life. She sees that she has a choice in how to manage this situation:

> *I think some people don't deal with it maybe quite like it I've dealt with it myself, em, I guess- I am quite strong I am quite a strong person and I think that makes quite a big difference to how you deal with it, oh I've had my times you know, where I've had wobbles [.] but on the whole, you know, I've laughed about things because [.] what else can you do, you know- it's frustrating, though … you have to, you have to deal with it, really […] yeah […]* (Kate, lines 1891-6)

In the quote above, Kate is saying that her underlying strength, which is a part of who she is, has affected her response to her experience. She presents as a strong, positive person with some control over her response to these distressing issues. This, she feels, aided her recovery from depression and her acceptance of the differences in her life post-CO exposure. Her identity constantly has to adjust to the changes wrought by CO exposure, and her life is full of constant reminders of the difficulties she now faces.

Be’s contribution here is about being identified by others. Once she found that the cause of the issues was CO, she encountered some rigid thinking from the healthcare professionals with whom she dealt and was, again, in a position where she perceived that she had more knowledge about the subject. She eloquently expresses this below:

> *You can give them as much stuff to make them aware, but if they have to, erm, they have made that, they have made their decision, that this is what you are, and- you hit this ceiling where, you [.] yeah you just can’t, or rather they hit a ceiling, you can go above that, but they cannot look further up [..] they are staring at that ceiling and that’s where they’re going to stay [..] er, and the sad reality is that the truth actually becomes meaningless [..]* (Be, lines 4356-661)

The *“this is what you are”* here is referring to Be’s mental illness diagnosis. She is saying that not only is this how they see her state of health, but tellingly, by saying *“you are”* rather than ‘you have’ a mental illness, it is clear that she perceives that this mental illness is all she is to the healthcare professionals, echoing the *“crazy lady”* subtheme. Rather than a person with a diagnosis, her perception is that healthcare professionals see that she has become identified *with* that diagnosis. She has described healthcare professionals at another point as being *“hell bent on this [..] she is psychotic [.] or it was she's neurotic”* (line 3543) which further supports this interpretation. Like Lizzie and Sarah, she feels that she is spending time talking to people who seem set on misunderstanding her.

Be’s manifestation of the struggle to maintain identity in her account is also strongly linked with the concept of justice. She talks of battling; at one point her husband *“was very proud of me for, having, taken on, it was this David and Goliath thing”* (lines 4092-3). She feels she was able to stand up to the conflict because of this identity as a fighter who was not afraid to take on a much more powerful challenger. The experience of CO exposure had profound effects, but Be wishes to change that by ensuring that there is legislation in place to protect people in her position and to ensure that issues around CO exposure, especially the longer-term exposure that she and her family suffered, become more well-known:

> *It took my life away but it gave my life back again [.] and I do feel passionate about it now [..] and I want to use my [..] I think that is my strength… [..] erm, in being able to fight for it, and but I do believe that no matter how much, how much [..] or how much amount of fighting you do, there has to be a foundation in place [.] that needs to change, to help people and that's what I want to fight for, is that legislative change?* (Be, lines 4538-42)

Early on in our first interview, Sarah talked about an important writing project connected with her work that she had completed during the first winter of her exposure. She gave me a sense of who she was in the time before her exposure and how she feels she has changed since the exposure in this quote:

> *I was doing that in the evenings and it was ok, like, and I was able to do that [..] like, I couldn't do that now, like, I just would not have the cognitive ability or the energy or anything* (Sarah, lines 34-5).

Like Kate, the cognitive effects of Sarah's exposure have had a devastating impact on her ability to complete this intellectual endeavour, and on her professional identity.

Sarah described coping with the situation throughout her experience as *"fighting tooth and nail"* (line 426 and 619). She identified with this warrior persona, and was further motivated by the fact that her case was not being treated as being in any way serious. At the time of interview, she was slowly starting to recover, feeling more *"like her old self"* (line 2985) when climbing into the loft to see the missing flue. Sarah's *"old self"* was active and vital, unlike the Sarah who was suffering from CO exposure. Her quote here speaks of her determination and passionate anger about the situation, which she could now express. The ladder and picture to which she alludes are the ladder that she borrowed to climb into her loft and take her own picture of the heating system's absence of a flue:

> *I felt, a little bit more like my old self, because I was like I'm going to fucking nail these guys to the wall, so the whole thing was I'm going to fucking nail these guys to the wall, I'm going up this ladder, and I don't care, … I'm going to find, this thing, and I'm going to photograph it, there it is, … I'm going to fucking get these guys* (Sarah, lines 2985-9)

This quote is also closely aligned to ideas of justice. Sarah is so angry that her experience and her illness through CO have been disregarded that she uses violent imagery, swears often, and she wants to see that those responsible are do not escape from being held accountable for their part in her experience; this is seen in the symbolic use of *“nailing to the wall”* which alludes to crucifixion or hunting; she will pursue the wrongdoers and ‘nail them to the wall’ to stop them. She repeats it for emphasis.

## Raising awareness

The focus on preventing CO exposure has led some, including Kate, to be keen campaigners. Campaigning is so important to Kate that she has engaged with factors she professes to find difficult or even *“traumatic”* (line 129), specifically reflecting on her period of suicidal ideation. She talks about being exposed to CO and the aftermath of the exposure for the charity and in her new work, taking every opportunity to prevent CO exposure happening to others in formal and informal settings. This commitment to prevention has its own affect and is seen in a positive and deterministic light:

> *I'm a great believer in fate (slightly laughing) and I think things happen for a reason, and obviously for me to go through it, is to help other people, and to, and to, you know, hopefully prevent, you know other people from going through what I’m, I’ve been through, so I don’t have an issue going through my story because I know when I, when I go to clients, and they say oh how did you get into, into [name of new career] [.] and I tell my story, it's like oh wow! Oh we haven't got one, or [.] you know, it brings it into people's homes then, and the awareness has risen since I’ve obviously been doing this, so, so yeah, I see it as a positive, yeah [...]* (Kate, lines 2198-205)

Kate is rewarded by empowering people to ensure their own safety, for example by doing something as straightforward as having a CO monitor and alarm. Be also is a fervent campaigner, working with a CO awareness charity – her choice of name (‘Be the change you wish to see in the word’) alludes to this desire for *“other families*” (line 26) to avoid exposure to CO. This has a profoundly positive effect; she feels that so much has been given to her by the charity that has helped her, and so in return she wishes now to be a part of the help that the charity gives to others:

> *Up until meeting, meeting [name of CO charity director], I just felt absolutely helpless, and I was, yeah, I hated life, I hated everybody, erm, and sometimes you just need a helping hand out of those situations [.]* (Be, lines 1855-7)

## Connectedness

As participants had been given the opportunity to focus on what was important to them through the data generation method, it was interesting to see how they began the first interview. While some launched straight into the account of what happened with the CO exposure, and others took pains to paint a picture of their lives before the CO exposure, Kate began by talking about the research itself, saying that she was *"so pleased that you, you know, that you're doing it, because this is, this has, been [..] needed, for a long long time"* (lines 31-2) while Be and Lizzie, to my surprise, both began by thanking me. I had been viewing the situation from my researcher perspective of gratitude to the participants for taking part and had not considered that affording them the opportunity to speak freely about their experience would be perceived as being so valuable to them that they spoke of it before anything else. Many of the participants expressed gratitude that the research was happening as well as interest in other people who have been affected and in the study itself, as a vehicle for learning more about CO exposure and lessening the isolation they feel. It appears that this caring, connected outlook formed part of coping with the trauma of CO exposure. Lessening isolation was something that was really important. As Sarah stated:

> *Yeah, I like hearing other stories, I like hearing that there's variety in there, I like hearing other stories, will bear out my experiences as well, and that we can bring them together [..]* (Sarah, lines 3183-4)

Sarah also states that her experience means she feels that she now owes a *"duty of care"* to the general public, perhaps indicating that she feels a responsibility to others as a result of her own exposure experience:

> *Honestly I feel like sitting on this information? And just saying, oh well, you know, I'm not gonna make sure this information gets contributed to better understanding of this, would be failing in the duty of care to other people, I know something now, I can't unknow it, other people need to [.] be more aware of it and look into it, you know, that's kind of my thinking* (Sarah, lines 3149-52)

Lizzie felt that others need protecting from what she experienced, and also saw participation in the research as a way of helping that desire to fruition:

> *I'm delighted actually that you're taking an interest because, the environmental impact, on people's lives aside from the terrible health toll, the losses incurred by families, it's [..] shocking* (Lizzie, lines 335-6)

Kate was also keen to hear whether her symptoms had similarities with those of others who have undergone the same experience, suggesting her desire for connection with others.

## Superordinate theme four: Everybody seems to be in the dark

This theme comprises the issues felt by some participants around the difficulties they faced as a result of their exposure to CO, namely, dealing with their unrecognised, non-specific symptoms, the complexities they had to manage when dealing with healthcare professionals, because of those symptoms, and finally coping with the aftermath of eventual discovery, which involves participants' struggles to obtain support. Figuratively, being in 'the dark' speaks of a state of ignorance, where someone is unaware, uninformed and/or oblivious to something that may be useful or important. As a difficult gas to detect, the effects of CO exposure, especially at lower levels, are obviously difficult to perceive even once identified through transient carboxyhaemoglobin levels. CO generally leaves no clear or visible mark among those who have been exposed to it, although the sequelae may be burdensome. The trauma that may have been associated with the exposure also leaves no obvious signs to the observer. These issues were represented in the subthemes 'I couldn't put my finger on it', 'ignorance and wilful ignorance', 'revelation', 'carbon monoxide does not exist' and 'other agencies and ignorance of CO'.

A key issue for the participants was that they themselves and many people around them were simply not cognisant of CO exposure as an issue in itself, particularly if they had experienced lower amounts of exposure over a longer period. Nor were they aware that even lower levels of CO exposure could cause damage that lasts, or that this damage might not present itself for a long time after the source of the CO had been eliminated.

## ***"I couldn't put my finger on it"* (Kate, line 196)**

Some participants experienced a prolonged period of perception that something was not as it should be before the cause of the problems was ascertained. Many experienced intermittent periods of non-specific and diverse symptoms, some of which were worrying and distressing, but which were characterised by their insidious, yet progressive, nature.

Sarah recalls that before her neurological symptoms became apparent, she noticed a change in her behaviour:

> *There was definitely a shift in my friendships [.] I didn't like, be immediately that winter like wow, I can't, cognitively, get my head around a lot of stuff, but it was like [..] I feel weird, I don't feel so good, I was feeling more emotional, I was having more kind of like, oh I just can't face going out with the friends, and everything started to get a bit rocky, and weird, it wasn't like clear-cut* (Sarah, lines 1273-8)

Her emphasis and repetition of the word *"weird"* show just how unusually she found herself to be feeling and acting – and how difficult it was to describe this – when seen in relation to her usual ways of being. *"Rocky"*, too, suggests that she feels as though she is on unstable, uncertain ground, where she was previously sure of herself.

Lizzie already had an ongoing health concern which was exacerbated by CO exposure. Here she describes the second winter of their residency, where *"we couldn't [..] understand what was happening"* (line 52). The 'him' in the first line of this quote refers to the family dog, who was also affected:

> *We moved here and then between him staggering about, and me staggering about [..] er, and the being unable to breathe [.] er, and the brain fog which was really thick [.] and [name of daughter], er, she had been a grand sleeper, er, but she started screaming [.] … and, and she was screaming about monsters in her room, and seeing things, and her ear drum burst the first year we were here, and then it burst again* (Lizzie, lines 566-71)

*"Brain fog"* is a subjective experience of having difficulty of any clarity of thought; the lack of clarity in turn suggests that there is haziness and no clear view of what is really happening. It is striking and symbolic of the insidious nature of CO, perhaps, that it cannot be seen and yet caused a *"really*

*thick"* fog as a difficult symptom for Lizzie. The persistent symptoms in addition to those described above that may have provided a clue to the CO exposure were *"irritability, sickness and diarrhoea"* and *"being a bit, vacant"* (line 595). These symptoms that Lizzie's children were experiencing which in hindsight can be seen as stemming from their exposure to lower level CO were not taken seriously by their GP. Sickness and diarrhoea are common ailments and can be symptoms of many viral and bacterial infections that spread rapidly between young siblings, especially in the winter months.

Kate's son was six when they moved into the house where they were exposed to CO. He started having symptoms which their GP ascribed to the child's *"just trying to, get out of school, basically, erm [.] nothing wrong with him, sent him off, never did any investigations"* (line 190-1). CO again was the cause of these symptoms, but remained hidden. Kate's own health deteriorated over months, but this was in a very non-specific sense, so that she reports feeling *"just not good, I couldn't put my finger on it"* (line 196).

Be described her youngest child's behaviour as a cause for concern, and, before CO exposure had been considered as a reason, something that she just couldn't understand:

> *She was shouting at us, and doing really, her behaviour was totally off the wall [.] smacking her head against the wall … she would literally go from being, very very sad, to, em absolutely distraught, to moments of euphoria, complete euphoria, where she would be jumping on the bed, as happy as Larry, it was just the strangest thing [.]* (Be, lines 143-8)

Be also, as her symptoms worsened, struggled to try and make sense of what was happening, and identify the cause *"I couldn't sort of [.] you just actually, couldn't piece things together, they were just all these pieces, but you didn't quite, you couldn't, get the story together"* (line 331). Be knew that at this stage her *"mind was coming in and out"* (line 330) and she could not find a cause for this. Showgirl's experience is slightly different in this respect, as although she could not confirm exactly what was happening to her, she deduced that her periods of feeling unwell coincided with her neighbour's habit of burning his building work rubbish in his fire place, where his chimney's liner might well have been faulty. A recurrent thought of hers was around the doubts over where the symptoms were coming from, despite her intuition. Like the other participants, Showgirl wondered about the origin of her non-specific symptoms; this was compounded by the thoughts of her friends and family on the issue:

> *I was just, you know when you're thinking, is it me? Am I just? [.] … you get people saying, oh well, what if, you know, you're getting anxious about it, and that's making you have the symptoms, and I'm not an anxious person … So then I thought, well, you know, are you making it, worse, than it really is, and you know, I mean, ideally, that would be the ideal situation and then there's no problem, is there? But, it wasn't [.]* (Showgirl, lines 138-47)

## Ignorance and wilful ignorance

Consideration should be given, at this point, to the insidious nature of CO, which perhaps accounts at least in part for the reason why people cannot identify CO exposure as the cause of symptoms. As previously mentioned, exposure to lower concentrations of CO over longer periods of time presents with vague, non-specific symptoms that could be associated with various other conditions, many of which may be self-limiting illnesses or could be explained away as something else. The symptoms that are commonly associated with higher levels of CO, such as seizure and coma, were not present and it may not have been appreciated that lower levels are so problematic, leading to a challenging situation for the participants who were looking for answers.

This lack of knowledge and inability to identify the essence of the situation around CO exposure was apparent in the care that the participants received from healthcare professionals in diverse settings, as the participants sought to understand and alleviate the various health concerns with which they were suffering. GPs were consulted before the discovery of the CO. Lizzie, Sarah and Showgirl were also seen by different consultants, Be was seen by paramedics and at A&E on several occasions and Kate was hospitalised for a week. In some instances, this led to lengthy investigations of conditions that invariably could not lead to a diagnosis of a physiological disorder, meaning discord occurred between doctor and participant when symptoms persisted and participants naturally continued to seek further explanation:

> *It's like your life is just slowly falling apart, and the doctor is saying there's nothing wrong with you, you're like [.] I know there is [..] and of course the only logical suggestion is, you're mental, that's what's wrong with you [..]* (Sarah, lines 131-3)

In this context, the use of the word 'mental' would usually convey a mental illness or be used as an insult, suggesting that Sarah was, for instance, acting illogically by insisting her doctor was mistaken in saying that she was not physically ill when she felt very ill indeed. Her certainty, conveyed by her emphasis, that there is something wrong seems to be no match for the doctor's apparent conviction that she is, in fact, not ill.

Sarah perceived that she was being dismissed; that as there was no immediate physical cause located in her body for her symptoms, the cause must therefore be an issue with her mental health. She was not alone in this thought. Lizzie and Be both perceived similar explanations from healthcare professionals. While Be was treated kindly by some, she also had difficult encounters where physiological investigations revealed no obvious cause for her symptoms. Her emphasis and repetition here show how unpleasant this was for her: *"I felt like a piece of meat, being thrown from one doctor to the next, and there's nothing wrong, there's nothing wrong"* (Be, lines 827-8). The use of this powerful analogy has been discussed.

Curstaidh, who was investigated for respiratory problems by her GP, felt that such investigations were a logical way of proceeding, demonstrating again how easily CO mirrors other symptoms. Curstaidh's symptoms were compounded by unsuitable living conditions, the landlord's refusal to address those conditions, and even the time of year:

> *C: and I think that's very typical, you know, you're presenting with 'X' symptoms [..] logic says you look at the history and I've had bronchitis as a child, I've had chest infections, it's another one [..] it's November, it's December, it's January, why wouldn't it be that?*
>
> *J: and they'd be asking if you smoked, and things, like that?*
>
> *C: yes exactly all of that sort of thing, … I, I had what I thought was a chest, an ongoing chest infection, in a damp house, that was a bit smoky [..] you know, (laughs) it all stacks up [..]* (Curstaidh, 192-202)

Although she was ill during her time of being exposed at home, much of the damage that Kate suffered only became apparent after the exposure was unearthed and the source had been eliminated. During her exposure, while she had many symptoms, they were non-specific. She did not often report feeling seriously ill, and was able to explain away these indications fairly easily; *"there was always a reason!"* (Line 1216):

> *It was just like I'd come downstairs and think oo [.] oo I feel a bit dizzy [..] and then it would go, and that would be out of my mind and then I wouldn't think then, and I'd go oh god I feel really tired, or [.] I just can't th- concentrate [.] but- there was always an excuse, there was always a reason, oh it's because of* (Kate, lines 1011-4)

This period included a week's hospital stay followed by a second admission with worrying chest pains, accompanied by ECG changes. The pains were such that she collapsed. Kate is young and healthy, with no risk factors for heart disease, and no cause could be found for her pain; again, another explanation was suggested when a consultant told her *"you've got classic, cocaine symptoms*" (line 220). In total, *"I got asked three times, I think, while I, on both visits, erm [.] and I said (laughs) no, definitely not cocaine"* (line 233), but *"at no point was I tested for carbon monoxide [.] at no point in all this*" (line 222). Kate's repetition of *"at no point*" perhaps indicates her frustration – the cause of her pain and collapse now seems obvious with hindsight. Healthcare professionals had the information they needed to have identified the true cause of her illness, but they did not consider lower concentrations of CO as a potential cause. As a patient, Kate perceived that her honesty was being called into question. She feels that had her doctors thought differently, the CO would have been identified sooner, but once the most common cause of chest pain had been discounted, the next explanation they sought was that she was a user of Class A drugs. This is where, for the healthcare professionals, it seems that the line of inquiry stopped; Kate must have been using cocaine and was refusing to admit to that:

> *They hadn't got a clue, basically, the cocaine kept coming up (laughs) I'm sure they didn't believe me (laughs) [.] that you know, I didn't take it, because that came up three times while I was- three different consultants* (Kate, lines 1401-4)

Curstaidh's GP treated her for her symptoms, while another GP in the practice treated her son for his different symptoms. Neither GP considered a shared, environmental cause: *"my own GP, with the best will in the world, couldn't spot it [.] em, and that's through no fault of their own [..] people simply don't know [.] and they don't look for that"* (Curstaidh, lines 129-133).

Curstaidh's reaction, that the GP did not know about CO *"through no fault of their own"*, is worthy of consideration. She feels that the lack of knowledge displayed by GP(s) on this occasion excuses their lack of consideration of her and her son's differing symptoms as a result of something environmental rather than physiological. Assertions of ignorance are not always a defence; however, Curstaidh feels that ignorance about lower level CO exposure is endemic, and therefore does not blame the individual GP, despite *"all the signs*" being present (line 180). Curstaidh, as indeed do all the participants, gives her account from the perspective of hindsight, where she now knows that what she and her son were suffering was the result of CO exposure over the period of months that they lived in that particular property. Since their exposures, all participants have learned a great deal about CO and its effects; Curstaidh can understand that her GP, who didn't have this knowledge, would just explore the non-specific symptoms with which Curstaidh presented.

Kate also reflects this perspective, saying that *"general practitioners, are that"* (line 1248), rather than *"miracle workers"* (line 1251) meaning that they deal with the general health complaints of the public. She expresses the hope that *"carbon monoxide poisoning, would be one of those things that [.] they do know about"* (line 1252), even though this was not her experience.

Lizzie had quite a different reaction from the GPs whom she consulted, and she regrets that they did not consider any other possible cause for her family's symptoms. She feels that she was not listened to because her existing misdiagnosis of Functional Neurological Disorder had labelled her as someone with a psychosomatic illness. Such a diagnosis is given when symptoms are present without any physiological reason, therefore suggesting that any other symptoms she complained about would also not have physiological causes and therefore not be serious or treatable. This speaks of a negative stigma around such conditions, where a person may be ‘malingering’ or ‘fabricating’ rather than ‘truly ill’. She deplores that that could have had the most severe of consequences for the family:

> *You know, if the doctors had, the first year, that that happened [..] I'm quite sure that that Functional Neurological, thingy, you know, it was just a dustbin diagnosis, whatever she says don't take any notice of her, she’s got, something weird going on, take no notice, get rid of her [.] if they had asked some questions that first year when I was saying, it's not just me, the plants are dying, the dog hasn’t got a leg to stand on, my children - there is not an area of this house that hasn't been puked on or shit on [..] … they were so poorly [.] not that a doctor took a blind bit of notice […] we could have died [.] we could have died, and they didn't ask any questions [..]* (Lizzie, lines 350-6)

To have a *“dustbin diagnosis”* is to have a diagnosis that is, essentially, rubbish, and perhaps indicates that Lizzie feels that all of her symptoms and opinions can be readily discarded by healthcare professionals; if there is no physiological sign that they are present, then they can, as happened to Lizzie, be deliberately rejected. Such a diagnosis can be given when a person has an unidentifiable condition, but it can also be used pejoratively to designate a disputed condition, such as Lizzie’s Functional Neurological Disorder. She feels that this diagnosis gave GPs licence to be *“blind”* to any other cause for her symptoms and to ignore her pleas for help, as all of those symptoms and pleas were merely a part of that psychological problem. The description Lizzie gives of her home and family at this time belies any notion of malingering, however. Lizzie’s family were overwhelmed, and the atmosphere was one of desolation and chaos. Lizzie expressed her anger at various point throughout her account; it was, however, quite rare for her to swear when talking to me, except when she wanted to convey particularly strong emotions.

During her exposure, Sarah grew increasingly frustrated with her interactions with dismissive healthcare professionals who did not know to look for CO exposure as a cause of her symptoms:

> *The doctors I went to were saying, no no, your thyroid is fine, this is fine, so you’re <u>fine</u>, you’re just tired go away, you know? [..] Doctors won’t – they just hate the word tired, and I didn’t have a better way of saying it, and they just weren’t really listening [.]* (Sarah, lines 1542-4)

Sarah refers to healthcare professionals being *"completely ignorant of their ignorance"* (line 293) when she talks about the lack of knowledge and evidence about lower levels of CO exposure and even the difficulty of having a blood test to confirm the presence of carboxyhaemoglobin. This indicates that for her, certainly, healthcare professionals do not appreciate the issues around CO exposure: *"there's no data, but people say this shit"* (line 1158).

Healthcare professionals are perhaps more accustomed to considering physiological rather than environmental dangers. They were not alone, however, in failing to recognise the cause of any complications. Gas engineers had, in the case of some participants, opportunities to discover that a problem existed, but failed to do so. Be's boiler was investigated several times for *"faults"* (line 2912). Lizzie's gas appliances were also serviced yearly, but the service had been carried out without comment and without identifying any problems during the first winter she lived in her house:

> *L: yes, yeah and I had spoken to the engineer for the time before, the year before, and said that I, I was very ill and was off work, er, but he didn't take any notice of that, but the second one, I didn't even mention it to him, he, was tinkering on with it, and he said, has anybody been ill? And I said oh god, all of us, aye, dreadfully ill [..]*
>
> *J: so he had his concerns straight away from looking at the fire, he knew what, what was going on-*
>
> *L: -he must have done, aye, he got me to stand outside for the smoke bomb, thing [.] and I can remember his face at that window, looking really frightened and he was, and I was going, no [..]* (Lizzie, lines 829-34)

The engineer who serviced the faulty gas fire in Lizzie's home in the first year the family had lived in their house, and the engineers who had previously carried out the servicing and safety checks in Sarah's flat, all without noticing problems, typify what Be classed as doing a *"Friday afternoon"* job, where the serious consequences of not checking appliances properly are not considered. She explicitly states effects of the situation:

> *This is a bigger problem than what everyone's making out [..] and these engineers, do not realise the significance of actually, that's fine, just making that statement, cos it's a Friday afternoon and I wanna get home [.] well by Monday morning, somebody might be dead [.] or six months down the line, a child's life might have been destroyed for life [..]* (Be, lines 1088-92)

It is beyond the scope of this work to comment on any matters of carelessness or negligence. It remains striking, however, that engineers also had the opportunity to recognise the cause of danger, but that this did not happen consistently for the participants here.

## Revelation

This subtheme is concerned with how the presence of CO as the cause of the problems became known to the participants who had been exposed for a longer period of time. Something hidden and undetectable, and yet which had been causing such havoc and harm in their lives, was sometimes revealed through chance.

For Curstaidh, this happened through a discussion during a meeting at work, where CO symptoms were discussed as part of a project and when she realised that what was being said applied to her and her son, because *"it mimics [.] features of colds and flu, it can give you headaches, it's colourless"* (line 72). Curstaidh initially downplayed the situation; as the nature of her work meant she was planning a scheme to help people detect any presence of CO in their homes, it seemed unbelievable that she could find herself in that very situation:

> *Er cos this may apply to me, I'm not trying to be melodramatic but I think it may, so he gave me a Toxirae monitor to take home, er, and told me how to set it, and everything and to set the fire, and [.] it, it went off the scale [.] I think they alarm it to something like, 30 parts per million and within minutes it had gone to 60 and above and above* (Curstaidh, lines 80-5)

Curstaidh's use of the word *"melodramatic*" indicates that she was perhaps wary of being thought to be overemotional and dramatically exaggerating her reactions. However, the *"off the scale"* response of the Toxirae monitor that confirmed that she and her son were in a dangerous situation in their home, as the level of CO far exceeded the standard safety level. She didn't want to appear unnecessarily fearful, perhaps as she was in a work context, but at home the alarm revealed a frightening situation.

For Sarah, inexpertly fitted loft insulation meant that a gas engineer came to her property to investigate the damage caused by the fitters. This fortuitous occurrence finally uncovered the far more serious problem that had been there all along and yet had been missed by both the yearly gas appliance servicing and gas safety checks. Like Lizzie, Sarah had been living with (and paying for) a spurious sense of security about her gas appliances. The eventual discovery of low-level CO exposure was therefore found by chance, despite a great deal of effort on her own part to try to establish a cause for her ill health. She feels that this is *"horrible"*" because of the lack of knowledge around CO and the chain of events that led to its discovery, from the inept installation to the engineer who was physically able to climb into her loft:

> *I mean that's the horrible thing, no matter what I did, it wasn't through anything that I did or any of my efforts or anyone of anyone else who was trying to help me's efforts, that it got discovered … it was just, an accident of someone else's random stupidity, like actually! [.] … and the fact that then, a gas engineer actually decided to check things out properly for once and I happened to get a young one who was still kind of, like, agile and willing to, make an effort* (Sarah, lines 2728-34)

Sarah and her friends had repeatedly tried to find out what was wrong with her, as neither her GP nor her consultants could find an underlying cause for the health issues she was experiencing. Again, however, no-one had thought to consider an environmental cause.

The discovery that exposure to CO was what was affecting their health was a revelation for the participants. This was typified by a sense of putting together the pieces – participants who had been exposed to low-levels of CO had not realised what was wrong with them and, except for Showgirl, had not imagined that it could be anything to do with an extraneous element, but were then faced with the realisation of what was causing their symptoms. Sarah's relief at finally having a reason for her symptoms is evident here; she expresses *"delight"* at being able to identify the cause of her health problems:

> *At first I was so in shock I couldn't, not tell people, you know, like I think I was a little bit like, blurty? But also, I was delighted, that I actually had, something to say, as opposed to saying, I'm feeling really sick, but my doctor says it's ok, which is a real conversation stopper [..] to be able to say [.] I have carbon monoxide poisoning, you know* (Sarah, lines 2962-5)

Kate's discovery motivated her to find out more. When she realised that something which had not been considered was causing her problems, Kate wanted to know as much as possible about CO and the implications of her exposure:

> *Obviously the first thing I did was Google it, long term effects I actually Goog- what's the long term effects, that's what I remember Googling, that's what I wanted to know [.] is, is, you know, is this going to have serious impact on my life, and then, lots of things made sense then to me [.] you know, how I'd been feeling, and the sickness and the dizziness and obviously when I collapsed and [.] you know, they didn't pick, they didn't pick anything up [.]* (Kate, lines 740-4)

## *"Carbon monoxide does not exist"* (Be, line 3757)

After the revelation of CO exposure, the consequences of the ignorance that surrounds CO were still evident for the participants. Participants researched CO exposure themselves, while their healthcare professionals remained ignorant and in some cases refuted the existence of any aftermath. GPs and A&E staff did not consistently recognise the next steps that the participants should take once recognition of CO exposure occurred. This seems to reflect the *"black or white*" statement made by Showgirl (line 475) and Lizzie about her perception of CO exposure as being a situation where it *"kills you, or it doesn't"* (line 220) – the implication being that people are expected to recover from any symptoms quickly and be recovered once they are away from any source of exposure, since CO is thought to leave the blood quickly. Sarah is concerned about the dearth of knowledge about and research into CO exposure, especially at lower levels, when she states:

> *They'll tell you, bare-faced, carbon monoxide leaves your blood very fast, but how quickly does it leave your brain, and your muscles? You know, and [..] argh, they act like they know, they say this crappy stuff like they know and they don't know <u>at all</u> [..]* (Sarah, lines 265-78)

Like all of the participants, Sarah has gained a great deal of knowledge about CO. She remains angry and frustrated, however (as conveyed by her emphasis, exclamations and repetitions), that the healthcare professionals in this quote are still dismissing her concerns. As far as Sarah is concerned, the healthcare professionals did not previously have a physiological reason for her ill health so they alluded to a psychological one. Once they were told that there was a reason, they still did not take appropriate action, and certainly not from an appropriate knowledge base.

Despite discovery, it took a long time for Be's account of how badly CO was impacting her family's life to be accepted, and she stated that despite her sharing of her knowledge about CO with healthcare professionals, they could not seem to accept CO as the cause of what they, the healthcare professionals, saw as her mental health problems. She says that *"they hit a ceiling"* (line 4358). The symbolism of a ceiling is interesting, suggesting that the healthcare professionals with whom she dealt are not able to see, or metaphorically, *"go above"* the knowledge that they have about CO to look at the situation from a different perspective, even after CO has been discovered. Some healthcare professionals were either then perhaps not aware that there could be after-effects once the source of the exposure had been identified and removed, or they were dogmatic in their assertion that CO did not have any after-effects for those who had been exposed over a longer period:

> *Em, and then you, you get told that actually, no, erm, there's no long-term effects of, of, of carbon monoxide, and you think to yourself, as a, a person with some common sense, how can you actually say, that six years of children being exposed to carbon monoxide at low levels does nothing to them? How can you as a medically trained individual say that?* (Be, lines 862-7)

Showgirl's consultant neurologist investigated her symptoms. However, she reflects that he did not have enough knowledge to make a judgement about her situation:

> *I asked him, the consultant … could my symptoms, be related, to carbon monoxide poisoning, and he said [.] long- cos I'm talking about low level, over a long time, not acute poisoning, and he said, well, when they did the MRI, he said [..] he basically said it would show up [.] there would be something on the scan that would tell us, you know, I was like, right, ok* (Showgirl, lines 443-50)

Showgirl's quote implies that a person's symptoms and history aren't as important as the tests which say there is nothing wrong. Kate, despite her memory and cognition problems and poor Kendrick (dementia screening) test results, also had a negative MRI scan, as did Be, who again shows a notable understanding of the issues of CO exposure and its effects on the body:

> *I mean, I've had an MRI and everything, and they say to me, oh there's nothing wrong, cos your MRI shows nothing, well, I can give you research studies where, people have <u>died</u> from the carbon monoxide and they've got MRIs of their brains and there's nothing there* (Be, lines 1518-20)

After a consultation arranged by her legal team with a doctor who had knowledge of CO, Curstaidh felt confident enough to ask her own GP to record the exposure:

> *And even when I spoke to my GP and said look [.] this- can you put this on my records, they [.] what they sent back to me was but we've got a cause [..] for your chest infection, and I said I know you have a cause, but there's a strong chance that this is the cause, so they did put it on, but it was [..] yeah, but we have something to pin it on, yeah but it may not be the right thing, and again I'm not suggesting [..]* (Curstaidh, lines 520-527)

As well as talking about the ignorance around CO, Curstaidh was alluding to the power that GPs have – when she says *"not suggesting"*, she is saying that she was not trying to be disrespectful towards her GP or to say that they were wrong in saying that there was another cause. Curstaidh was aware that due to the nature of CO, the truth about her 'chest infection' could continue to be elusive; was it somehow caused by CO? Was it exacerbated by CO? Was it 'just' a chest infection, despite test results to the contrary, that coincidentally appeared during the time of her exposure to CO?

Lizzie phoned her doctor while the engineer who discovered the low-level CO exposure was still in her home, reflecting her immediate concerns about this revelation:

> *L: while he was actually there, tinkering about, I lifted the phone to the doctor's, and said, oi, this guy here is saying we've got carbon monoxide, could that be what's caused? [..] And she was very noncommittal, very noncommittal, she wouldn't say [.]*
>
> *J: did she suggest blood tests?*
>
> *L: did she shite* (Lizzie, lines 845-9)

Lizzie's GP countered her active stance here by being unwilling to investigate any further issues that may be causing or exacerbating symptoms when a diagnosis had already been made, much to Lizzie's disgust.

Kate has seen many healthcare professionals in the time since her exposure was discovered. She finds that a commonality between them is that they will not commit to stating that her numerous problems have been caused by her long exposure to CO:

> *We think it's carbon monoxide, but, we, we're going to sit on the fence because we don't, we don't want to put our name to it, but actually yeah, that's what's caused it [..] so, we think it is, but we're not, you know, we're not sure [.] so that's how they, how they sort of dealt with it [.]* (Kate, lines 272-4)

Kate and Be both use the term *"no man's land"* (Kate, lines 1547 and 2404; Be, lines 991, 1005 and 4317) to clarify this situation. This term depicts a powerful metaphorical space with connotations of war and desolation, as well as the reification of the concept of a fundamental struggle between two warring factions; in this case, between participant and many of the people whom they had contacted for support. The participants can also be envisaged as being jammed in no man's land between the CO exposure and the unsupportive people who refute the effects of that CO exposure. The metaphor can also function as a reminder that a person in no man's land is lost or stranded as well as being isolated. Kate's exposure was, at least, straightforward to acknowledge, and it was agreed that it had caused some damage, but she found it isolating that any concrete facts were difficult to obtain from healthcare professionals, who again refused to take a stance but instead would *"sit on the fence"*:

> *They sit on the fence and say [.] possibly it could be [.] but who knows? [.] So it's, it's you know, you're in no man's land really with it, so that was frustrating, and I've seen some of the top 'experts' in the country, and they've all much, as I say, Professor [name of toxicologist], that was the classic one for me … you probably know more about carbon monoxide poisoning than I do* (Kate, lines 1546-50)

For participants, the effects of low-level CO's very existence are denied and there are substantial barriers, such as a fog-like, smothering *"blanket"* to even discussing it, as Be says:

> *It's just there's this, this blanket [..] they <u>will</u> not [..] it's like carbon monoxide does not exist [..] that's what it comes down to [..] erm, that you are [..] the whole way through this you have been- had these psy- this <u>long</u> psychotic moment, and imagining these things that are not there, that's what it feels like [..]* (Be, lines 3757-60)

The *"blanket"* of the refusal to acknowledge that there may be another cause than the original diagnosis suppresses Be's senses, just as the CO itself does. It also serves the function of keeping Be at a fixed point of time. Where time progresses as usual for people not exposed to CO, Be's whole experience is akin to a *"long moment"* of psychotic illness.

The final point in this section refers to the remedies that some of this group sought for themselves, driven by frustration at the lack of acknowledgement about CO exposure from healthcare professionals. After initially being refused any investigations or treatment, Sarah *"went my own way"* (line 270) and arranged some hyperbaric oxygen therapy for herself, as she remained unwell and a level of carboxyhaemoglobin persisted after the exposure was recognised. At the time of interviews, Sarah was undergoing this treatment; she told me that the doctor there had an aim, which is:

> *Not to get you like, under 1.5 or anything, our aim is to get you way way down, because, you know, we want to make sure that everything's drained out of all the tissue"* (Sarah, line 610).

Kate and Be also discussed the use of hyperbaric oxygen therapy for those with lower level exposure to CO.

Be stopped taking her prescribed medication for her mental health symptoms due to an article she had read that stated the potential for adverse reactions between psychiatric drugs and mental health symptoms caused by CO exposure, with the drugs exacerbating the symptoms. Be also uses vitamin B12 injections, which Kate also discussed in interview, as did Sarah in a post-interview communication. Be is very positive indeed about vitamin B12's effect on her sequelae, saying that it has *"transformed her life"* (line 1378).

## Other agencies and ignorance of CO

As well as healthcare professionals, other agencies were also involved in the issues surrounding participants and their exposure to CO. This changes the framing of participants' problems away from a purely physical or psychological issue, situated within the participants' bodies, as healthcare professionals tended to see them, and instead situates the issues in a wider environmental domain. These other agencies included the aforementioned gas engineers and people connected with housing infrastructure, such as landlords, legal and bureaucratic officials, those working for Non-Governmental Organisations and Environmental Health Officers. However, the same difficulties existed in identifying the cause and scope of the problem as well as defining the correct action to take once the issue was identified. This quote exemplifies this theme, as the emphasis and repetition tell us about level of knowledge about CO that can be found at Citizen's Advice: *"when I spoke to people at Citizen's Advice no idea what I was talking about [..] <u>absolutely</u> no idea […] really no idea [..]"* (Curstaidh, lines 518-20)

Showgirl added clarity. There is some awareness of some of the issues around CO, she feels, but only around higher level, fatal exposure:

> *It seems to me that they only know about it [.] when it's very serious, like one of the firemen* (sic) *was telling me about a case … and they went, and there was a couple [.] sat on the sofa [.] with books? [.] Dead [.]* (Showgirl, lines 790-2)

Be's family had been referred to Social Services, as her diagnosis of a mental illness was thought to be cause for concern. Her emphasis on certain words and her repetition of the word *"irrelevant"* in this passage conveys the frustrating nature of this meeting with authority figures, where there is a feeling of interrogation:

> *Social services were called in [.] and they came to the house, and they questioned me, and <u>everything</u> I said, and <u>everything</u> I shared with them was met with the words, that is irrelevant [.] I have <u>never</u> heard those words spoken to me as often in one conversation, as I did that day [.] that is <u>all</u> that they said to me, that is and everything that was irrelevant was what my doctors, had, had not looked into, what my doctors were saying, and I was countering, was irrelevant [.] everything I had to say, was irrelevant, so basically, if I'd have not toed the line and listened to what they were saying, I, it was irrelevant [.]* (Be, lines 604-10)

Be did not feel supported by this encounter with Social Services, and speaks of feeling strongly that she was *"having to toe the line"* and unwillingly accept their position in order to keep her family together; Social Services had no concept of CO and the damage it could and indeed was causing her family, so while she was trying to tell them that her and the children's symptoms and behaviour could have an environmental cause, they did not accept that.

Showgirl reported her errant neighbour to Environmental Health after trying but failing to reach any accord with him herself. The Environmental Health Officer, however, clearly did not have the same level of knowledge that Showgirl has about CO. Here, Showgirl relates the Environmental Health Officer's revelation of her own lack of understanding about lower level CO:

> *The head of Environmental Health, I had her out here as well, and she was, her attitude was terrible, er, she, she was [..] ah, I don't know she just she didn't have any knowledge either [.] and she kept saying, well, your alarm hasn't gone off, so, how can there be a problem? And I'm like, ahhh, so I was trying to explain to her, you know, and she said, I can see you've done a lot of research [.] I said, well, I've felt I've had to! [.]* (Showgirl, lines 186-92)

That the Environmental Health Officer would not acknowledge any problem with exposure to lower levels of CO *"that wouldn't bother your alarm"* (line 136) is worrying, and reflects the message of this superordinate theme, which is that when faced with issues of CO exposure, none of the relevant agencies with whom the participants had contact had enough knowledge to correctly address the issue. As Sarah tried to tackle her own situation, she educated herself in the correct bureaucratic procedures around CO exposure, and realised that those who were meant to already understand and action those procedures did not always do so:

> *[Name of gas providers], should have reported a RIDDOR, you know, a, a, notification of, of not being safe [.] and they didn't, and I actually rang [name of gas providers] shortly after, I knew the manager was involved and I said … are you putting in a RIDDOR, this was around the time I'd found the HSE website, and he said, I don't know [.] and I'm like, you're the fucking manager, how do you not know?* (Sarah, lines 414-19)

In fact, it seemed that there was very little support available for these women to seek, resulting in a round of exhausting, ineffective and repetitive queries. Sarah *"was phoning Shelter, I was phoning Citizen's Advice, I was phoning everyone saying, where do I go with this? Where do I go with this complaint?"* (Sarah, lines 365—7). Her feelings are echoed by Curstaidh, who states:

> *The only reason I can think of, you've got the council going oh, nothing to do with us [...]… so, it's a really difficult area [..] em, and so you've got people who are in the position of being*

> *able to enforce the law [...] who don't actually have the knowledge [..] to be able to do it [..] so who do you turn to? Cos Citizen's Advice knew nothing about it [..] [name of town council] didn't know anything about it, er, what do you do? Most people give up* (Curstaidh, lines 606-17)

Curstaidh's account is of a struggle with her landlord, who refused to take responsibility for the low-level CO that she and her son were exposed to, and the fact that she, as an articulate woman living in a developed country with a sophisticated infrastructure, could not be helped in this situation, despite trying many avenues. She is circumspect about this aspect of her experience now, but recognises the enormity and potential for fatality of the situation when she states:

> *It did highlight a number of different areas where people just don't have an understanding of the magnitude and the, the [..] deadliness [...]* (Curstaidh, lines 630-3)

## Summary

This chapter has presented findings from the data presented by group two. I have here conveyed the effects of the traumatic experience that is exposure to lower-level CO, including issues of traumatic effect and inherent problems in dealing with healthcare professionals who do not have understanding of the complexities of CO exposure, and a concomitant lack of agency for the participants. I have presented ideas around identity and connectedness, which is relevant to both groups. The next chapter will address these themes both in relation to the literature and in the discussion of new literature; following the inductive approach of this work in giving a voice to those who have experienced CO exposure, far more has come to light than is present in the extant literature about the subject.

# Chapter eight: Discussion

# Introduction

This discussion chapter will build on the findings of the previous chapters. Within this study, I aimed to explore the lived experiences of 11 people who had been exposed to CO, in order to gain insight into what the experience of CO exposure and the aftermath of those events felt like for those individuals. The intention was not to provide an empirical explanation of CO exposure, but for the participants and me to explore how those who have been exposed make sense of what happened to them. As well as looking at the findings in relation to the previously explored work around the literature on CO and coping with traumatic experiences, the findings led me to new information whose relevance to CO could not have been considered before data generation, as I was led into *"new and unanticipated territory"* (Smith et al., 2009 p.113). All of these elements will be examined in order to answer the research questions of:

- What is the experience of people who are exposed to CO?
- How does the exposure affect their lives?
- How do they experience the aftermath of that exposure?

Tracy (2012) affirms that the inductive nature of such work leads to new lines of inquiry which will also be presented and incorporated into the data in order to explore the phenomena contained therein (Bloomberg and Volpe, 2019). A lack of *a priori* rationale means the data analysis cannot always be directed by the literature, and is entirely appropriate for this form of qualitative research (Tracy, 2012); therefore, discussions on diverse subjects as power, health and living with chronic illness shape this chapter.

Firstly, I enter into a dialogue between the literature on coping with trauma and the findings. This is followed by some convergence and divergence between the current findings and the literature on CO which was explored in chapter two, especially regarding the lack of knowledge about the issues. For many participants, the issues of coping with their trauma was not a substantial part of their account, so although some points regarding problem and/or emotion focused coping are highlighted here, it was not my interpretation that a specific mapping of ways of coping with trauma and what participants did in this regard, formed a necessary part of this discussion.

The discussion that follows this section is about power. This includes moral judgement and the effect of stigma in illness, and gender, with regards to issues such as the lack of treatment and recognition around CO exposure, all of which were introduced by the participants. Issues of identity and connectedness, again introduced by the participants, form the concluding section.

## Coping and trauma in CO exposure

While I anticipated that exposure to CO was a traumatic experience for those involved, I could not anticipate how that trauma would manifest, nor how the participants would express their experience of coping with it (Smith et al., 2009). The inductive approach of IPA allows for deeper exploration of traumatic experience and coping in light of what was disclosed by the participants in the previous findings chapters, with regards to their different experiences of CO exposure. This section draws together the participants' experiences of CO exposure and its aftermath in terms of coping with trauma. There is a further layer of complexity here. Although it is impossible to separate the two effects, CO itself can have negative cognitive and affective impacts on those who are exposed to it (for example Pepe et al., 2011; Roderique, 2015; Hopkins et al., 2006), and trauma itself can also have profound effects on physical and mental/emotional health (Khamis, 2015).

Although it is not possible to know how close participants such as Be and Lizzie were to dying, they certainly perceived and feared that this could happen. Feelings of fear specifically featured in the accounts of Be, Lizzie and Sarah over the protracted period of their exposure, which could be indicative of neurotrauma (Medved and Brockmeier, 2008) from CO exposure (Hopkins et al., 2006) as well as psychological trauma. Death also affected the dyad of Tisha and Ajay as their downstairs neighbour died, and it was also a distressing realisation for Tisha to be shown the graph of CO symptoms that led to her realisation of how close to death she and Ajay had come themselves. Matt too experienced the acute dread of thinking that he was going to die.

While it is not my intention to define trauma for others or attempt to 'diagnose' a trauma-related condition such as PTSD, as the aims of the research are concerned with how people experience the exposure to CO, discussions on trauma in the literature do involve definitions. People who are exposed to CO in certain contexts, could be considered to have experienced a trauma as defined by the DSM-V; the potential for their own death is strong and immediate and they suffered serious physical injury (APA, 2013). Conversely, the experiences of those in other contexts, for instance where the exposure happened over a longer time, perhaps would not be defined according to the DSM-V as a true trauma (Pai et al. 2017). The risk of death in any case could not be accurately estimated for these participants, as the concentration of CO to which they were exposed is not known. However, as stated by Wang et al. (2019), the occurrence of the exposure to CO indicates that all participants' experiences here are traumatic, as they experienced them as such. Reyes et al. (2008 p.*x*) define trauma as resulting from events which are *"emotionally shocking or horrifying"*, involving or containing the likelihood of imminent death, and are out of the affected person's control. All participants considered the traumatic nature of the CO exposure and the sequelae to be the substantial aspect of their experience; Ehlers and Clark (2000) and Weathers and Keane (2007) consider negative appraisals of trauma and/or its sequelae to be indicative of the development and maintenance of symptoms of trauma. The elusive and insidious nature of CO, as the 'silent killer', and the concurrent lack of knowledge about the subject, appears to add a further dimension of underlying trepidation, especially when considering that some participants endeavoured to find out the cause of their symptoms, but could not. They often did not know what the outcomes would be once CO was recognised as the cause of their health problems, and they were not always heard when speaking about CO exposure; all of these elements added to the traumatic effect of the experience.

Some of the trauma of being exposed to CO developed, therefore, as a result of the exposure itself, or its immediate, short- and long-term effects on the individual and the people around them, and also, in some cases, as a result of the people around them, or a combination of all of those factors. This is in concurrence with Reyes et al. (2008) and Pai et al. (2017), and their references to the experience of catastrophic life events.

Kate, Bookie and Sarah all discussed their own deaths in terms of their depressive feelings subsequent to exposure (Weathers and Keane 2007; Reyes et al. 2008). Kate was clear, in hindsight, that for her, her thoughts about ending her own life were a direct result of her CO exposure. Sarah expressed these thoughts in an almost matter-of-fact way that she compared to *"the idea of … euthanasia"* (Sarah, line 3385), while Bookie, although not expressing explicit suicidal ideation, when talking about his mother's death stated: *"sometimes, I wish I'd gone with her, you know?"* (Bookie, line 663). Be also expressed some suicidal ideation. Tarrier and Gregg (2004) report the apparent strong connection between chronic PTSD and suicidal ideation in their research with non-military participants. For these participants, the same appears to be possible. However, as with other traumatic effects reported here, the contribution of CO exposure itself cannot be accurately assessed.

## A divergent theme: Questioning the world-view after trauma

When discussing her trauma, by questioning why CO exposure had happened to her and Ajay, Tisha questioned her world-view. She talked about the counselling sessions she needed, where she questioned why she had gone through the exposure and why she had survived as an expression of her feelings of trauma. This questioning shows the challenges that were made by her traumatic experience to Tisha's world view. Janoff-Bulman (1989, 1992) and Janoff-Bulman and Morgan (1994) assert that most people have essential assumptions about the *"internal world"* (Janoff-Bulman and Morgan 1994 p.58) or the cornerstone of a deeply conceptual system; namely, that the world is benevolent, meaningful, and the self is valuable (Maschi et al. 2010). Belief in a meaningful world means that often people find difficulty in positioning such traumatic events as exposure to CO as random or chance, meaningless occurrences, as these assumptions support the powerful premise that unpleasant things cannot happen. Although perspectives on previously-held benevolent world-views did not form part of the participants' accounts, it can be seen that some assumptions of a benign world-view have been shattered here, and Tisha voiced that by saying *"why me?"* (Line 570).

## Problem-focused coping

It was clear, as stated, that all of the participants had learned a great deal of information about CO and its effects. While conversations did not typically extend to levels of knowledge about CO before exposure, I was continually impressed by the wide-ranging knowledge that they now possessed and discussed with ease and authority. Vivienne, Be, Kate, Tisha and Ajay use this information in the work that they do with charitable organisations and Sarah wants to affect change regarding CO in her own work environment. The other participants, perhaps especially Matt, have a deep understanding of the issues around CO exposure and its aftermath. None of the participants avoided the subject of the stressor, their CO exposure (Littleton et al., 2007). Avoidance could be maladaptive in coping (Snyder and Pulvers 2001), but this gaining of knowledge and the raising awareness activity are aspects of problem-focused coping. They reflect Folkman and Moskowitz's (2004) and Khamis' (2015) ideas about how people cope with traumatic events in their lives in different ways, namely the two broad concepts of emotion-focused and problem-focused coping. This issue is particularly important here as recovery is aided by an individual's own knowledge and perspectives of their condition (Resnick et al., 2004). Issues of control over the situation are also relevant here (Littleton et al., 2007), as problem-focused coping strategies are thought to be of more use to an individual in situations that can be controlled to some extent (Folkman and Moskowitz 2004). In the aftermath of exposure, control over the situation, or gaining control, seem to be relevant issues for most participants. All participants had subjective experiences of CO exposure, and variables such as age, gender and personality traits (Matthews et al., 2015; Maschi et al., 2010) were not taken into account in this research. However, these are interesting features in terms of coping styles and their uses, which may form a basis for future work.

Learning about CO exposure as a way of coping can be seen as a part of a set of skills of which resilience is the implementation (Stratta et al., 2015). Many participants displayed notable resilience. Kate, for example, has many burdensome sequelae. She has had to change her career and may yet have to do so again, due to her ongoing consequences of exposure, but feels that she has *"come out of it"* – *"it"* being the worst of the experience – and is *"doing positive things"* (line 1631). She attributes her resilience to her personality traits (Matthews et al., 2015).

## A divergent theme: The one left behind

The deaths of Vivienne's partner and Bookie's mother through CO exposure constitute traumatic bereavement, which occurs suddenly, without warning, or under traumatic circumstances, and is known to cause sustained feelings of being completely overwhelmed by that loss (Reyes et al., 2008). Barlé et al. (2017) contend that the symptoms of trauma and grief that are felt after such a loss are substantially more severe, pervasive and prolonged than after a more natural death. Both participants, for instance, showed yearning for the person whom they lost. Bookie in particular disclosed his experiences of previous, sudden losses of close family members to illness, which he shared with me in order to set the context of his account. He found his mother's sudden death to be difficult to cope with when he compared it to the loss of his father, brother and aunt. Although he had been close to those family members too, it was with his mother that he shared the closest bond: *"lads are closer to their mums"* (line 789), and the circumstances and aftermath of her death were hard for him to bear. A bereavement can also be considered traumatic if a survivor regards the death as preventable (Malkinson and Brask-Rustad, 2013). Bookie's experience of his mother's death and the aftermath of that death was certainly further complicated by the triggering of guilty feelings that he experienced, and the protracted court case that followed in which he did not feel that justice was served.

Vivienne's partner was a young, previously healthy woman. He vividly described her to me as a vital individual with whom he was very happy. Traumatic bereavement is also said to occur when the survivor's own life is threatened, as happened in both these settings. Vivienne and Bookie both had to summon help for themselves, with the added complication for Vivienne that he was injured, ill, and isolated, as well as having to contend with sudden and shocking bereavement. In other signs of traumatic bereavement, Vivienne painted vivid pictures of his waking next to his partner's body (Barlé et al., 2017; Malkinson and Brask-Rustad, 2013); Bookie has also experienced some bitterness as a result of his mother's death (Reyes et al., 2008).

For those who suffer a traumatic bereavement, disorders such as depression, anxiety and PTSD symptoms may occur simultaneously with grieving (Reyes et al., 2008), where *"grief symptoms are overlaid with trauma symptoms"* (Barlé et al., 2017 p. 128). Malkinson and Brask-Rustad (2013) contend that there are *"distorted cognitions"* (p.114) associated with traumatic bereavement, as, of course, there may be with CO exposure and its affective and cognitive impact (Roderique et al., 2015; Pepe et al., 2011). This situation may therefore be far more complex for those bereaved by CO when they were also exposed, as Bookie and Vivienne were.

Both have daily reminders of their loss, which again can add to the burden of traumatic bereavement (Reyes et al., 2008). As well as the absence of mother and partner in their lives, Bookie's court case was protracted and the CO exposure and aftermath changed his life dramatically. Vivienne has the additional impact of his loss and the physical, life-changing injury and scarring to his arm. Macleod et al. (2016) discuss the effect of such reminders as triggers for re-experiencing the traumatic event, where the trauma and grief symptoms, alongside those reminders, act as mutually maintaining.

## Trauma-related guilt

For Bookie, guilt is a complicated process as he was offhandedly advised not to turn the boiler on, however, the actual responsibility for this lay with the worker who gave him incomplete information.

The coroner later stressed that none of the guilt was Bookie's. Vivienne's initial response to his arrest, even though he could not imagine that he had committed any wrongdoing towards his partner was to visualise appearing in court charged with murder. Although this response was quite-short lived, it added considerably to his distress. Lizzie also feels guilty; she feels that she should have somehow recognised what was happening sooner, but again quickly realises *"there was <u>no more</u> that I could do"* (line 661). Tisha felt guilty for not safeguarding herself and Ajay by having a CO alarm. Matt felt guilt for not protecting or defending himself. This guilt is connected to a previous general lack of knowledge about CO and the dangers that it poses, but these participants have here internalised this lack of knowledge. Although lack of knowledge about CO is endemic, to varying extents the participants see that there is some measure of blame that they bear; it remains uncertain whether they could have protected themselves if more was generally understood about CO, but knowledge about CO is rare (Coquet et al., 2007; McDonald et al., 2010; Jafaru, 2015).

Trauma-related guilt is documented as post-trauma reaction (Browne, 2012). Guilt experiences are defined as *"regret regarding a transgression or self-perceived wrongdoing"* (Tignor and Colvin, 2018 p.2) and can manifest themselves in various ways, from short-term discomfort to substantial and long-lasting anguish. These authors state that guilt is a personal experience that people perceive through social situations, whether there is actually anything inherent in that situation to 'feel' guilty about or not.

Ajay's comments in response to Tisha's disclosure of feeling guilt for not thinking of buying a CO alarm are particularly pertinent here, and apply widely. He comments that people have heard of CO but do not have knowledge, as it is not publicly discussed. He compares the situation about CO knowledge to that of drink-driving which, he says, has been *"hammered into us"* (line 1187). Many years of advertising the dangers and consequences of driving after consuming alcohol mean that few people are unaware of the inherent risks of drink-driving, and so public practice has changed and far fewer people are killed as a result (Drink Driving.org, 2019). Ajay's point is that the same needs to be done with CO. If the dangers were so publicised, people would automatically know how to protect themselves from exposure and behave accordingly.

Lee et al.'s (2001) theory of guilt-based trauma states that guilt occurs when the significance of a traumatic event induces feelings of responsibility for harm, especially through hindsight; for example, Vivienne and Lizzie experience the feelings of guilt but can realise that logically, and as time has passed, the feelings are not apposite. Tignor and Colvin (2018) further define trait guilt as largely maladaptive and a characteristic of those people who have a tendency to experience guilt more often or to a greater intensity than others.

## **Existing knowledge about CO and the experience of exposure to CO**

The literature on CO and medical science represents what is currently available for furthering an understanding of the effects of CO exposure on people. As stated from the outset of this research, however, the perspective of that literature is that of the healthcare professionals who authored the papers that comprise that literature, meaning they deal solely with bodily systems and their response to CO exposure, rather than the perspectives and lived experience of those who actually suffered the exposure. Writing from a perspective of the lived experience of those who have been exposed to CO, which has not been done before, means that the extant literature on CO becomes problematized (Smith et al., 2009). This is because there are limited parallels or lines of discussion which can be derived from that CO literature, and there are substantial distinctions between the lived experience and the described case studies found in that literature. Nevertheless, there are some salient points which I will now make in terms of both convergence and divergence between the existing literature and the current findings.

It can be seen from the findings that CO exposure had a profound effect on the health and wellbeing of all participants. While the circumstances of their exposure varied, all participants had a tangible reaction in the form of symptoms and aftermath. For some, such as Vivienne, Tisha, Kate, Sarah, Be and Matt, health conditions lingered. For others, for example Be, Sarah and Lizzie, in addition to living with the aftermath of CO exposure, relationships with healthcare professionals were adversely affected which had a considerable impact on their experience. For Bookie and Vivienne, as discussed, bereavement remains an important consideration; all of the aforementioned factors impinge on the health and wellbeing of participants. For these reasons, I will discuss some theoretic concepts around health, as well as the experience of the symptoms themselves. This is done to help the reader further explore the ways in which these issues affected the participants, whose experiences related to their own health and were situated within the power dynamics and relationships of the health system. All participants in both groups contributed to the key theme of power, justice and judgment and it is largely from within the findings in that theme that the following discussions arise.

## Defining health and illness in CO exposure

I will now explore positions about health, illness and disease, incorporating how these notions pertain to the participants' experience of exposure to CO. I will include a brief discussion of the complexities already inherent in defining health and illness, as well as of the medical model, its perceived dominance and the consequences of that dominance for the participants. I will also use the term 'layperson' to talk about those seeking help from healthcare professionals. Discussions about health and illness are relevant as they allow consideration of the complexities in identifying CO exposure and its aftermath. Anyone exposed to a high concentration of CO would certainly be defined as being very ill indeed, and some will develop chronic issues that require further care (Arasalingham et al., 2015). The situation is, however, more complicated for those with exposure at lower concentrations. These people do not easily fit into a category where they can be diagnosed, and I have established that there was a great difficulty for many participants in communicating their problems to healthcare professionals. They often presented with non-specific symptoms that did not lend themselves to a diagnosis of serious import, and yet their health continued to deteriorate.

These symptoms were severe at times, for example, Kate's collapse and week-long hospitalisation with chest pain and Showgirl's several near-collapses. Treatment options are also limited and contested in all cases of CO exposure.

Health, illness and disease are fundamental concepts (Hofmann, 2005); institutional and primary healthcare account for a significant proportion of the expenditure of any country (Illich, 1976; Blaxter, 2010). Attempts have been made to elucidate these terms; for instance, 'health' has been seen as nothing more than an absence of 'disease' and 'illness' (Sartorius, 2006), and 'disease' can be scientifically classified. It is a cornerstone of the human condition to experience disease and illness (Blaxter, 2010). Disease can mean changes to the mechanisms or organs of the body (Fox, 2012) producing unwanted effects which are experienced as symptoms; illness has long been viewed as a subjective experience of disease (Stenback, 1964; Kleinman, 1978; Fox, 2012). This subjectivity renders definitions of any norms about illness even more difficult (Blaxter, 2010) as perception invariably differs among individuals and in different contexts. If, however, disease is caused by factors such as infection, vector (where an agent such as a parasite transmits the pathogen), environment or genetic susceptibility, then it is a property of the physiological body (Moncreiff, 2017). This reductionist – and thus, for authors like Shah and Mountain (2007) and Thompson (2019), unfavourable – thinking can lead to the exclusion of social and psychological factors (Nettleton, 2013) as well as the exclusion of the layperson's experience. This latter should remain a central feature of healthcare (DoH, 1997; Fox, 2012; Kleinman, 2013), as CO exposure impacted on every aspect of the participants' lives, and the lives of their families.

Disease can also be seen as deviance or as a fault to be rectified (Poti et al., 2017): *"the objective observation of a lack of 'normality' meets a very ancient and universal tendency to see the sick person as in some way morally tainted"* (Blaxter, 2010 p. 7). This statement alludes to a possible choice or choices that the sick person has made, or could make; perhaps they carry some blame for their condition due to a particular behaviour, for example. This also concerns previous discussions of guilt, where the individual lacks knowledge or behaves in a way to the detriment of their health.

Concepts of illness and health can be complex; an absence of disease does not necessarily mean that a person is healthy, but the converse is also true (Thompson, 2019). An absence of health (such as in a well-managed chronic medical condition) does not mean that an individual cannot feel subjectively healthy (Larkin, 2011; Blaxter, 2010). The idea of illness as a subjective experience can cause conflict at times among healthcare professional and laypersons, and this can be further complicated by the power dynamic that exists between them. This concept especially applies to Be, Lizzie and Sarah, and will be explored in more depth in a later section. Kleinman (2013) also postulates that the latter point holds due to the tendency of medical science to attempt to apply a scientific classification of disease and treatment to people. Again, there is further complexity inherent here, as although medical science is seen as a scientific endeavour, it also provides *"succour – a source of relief or assistance in times of distress"* (Collins and Pinch, 2005, p.2).

## Medical model thinking and the 'sick role' in CO exposure

The medical model, sometimes referred to as the biomedical model (Sheridan and Radmacher, 1992), has been used to discuss these concepts of health and disease, including the relationships between them, as an explanation for the aforementioned scientific classification of disease. The model has also been used to illustrate concepts between the layperson living with disease and the healthcare professional. The role of the healthcare professional within the medical model is to move the sick layperson along the continuum of health from a state of illness to a state of wellness (Roy, 1970). This perspective is analogous to the idea of a body as a machine. All working parts can be treated separately, and health is present when all are working, together, as they should (Clarke and Everest, 2006). In conjunction with the imagery of the continuum, Nettleton (2013) asserts that the history of medical science itself is one of advancement; that there is a progressively accurate knowledge of disease and disease states. Concurrent social context and determinants of health are not usually considered from this perspective (Iacobucci, 2018; Nettleton, 2013); the focus is on the physical aspects of the individual.

However, the medical model does not clearly explain health and disease being present at the same time (Hofmann, 2005). As a concept, the medical model is also somewhat problematic to define, although it has been recently referred to as *"dominant"* and *"seductive"* (Iacobucci, 2018, p.1). Fawcett (2017) advises that it seems to be something which is often referred to without clear demarcation, as though a reader would simply *"know what the term means"* (p.77); she states that no clear definition can be found. Blaxter (2010), however, concurs with Sartorius (2006) and Kleinman (1978; 2013) when she states that the model is based on the disease that needs to be treated, and is therefore focused on ill-health and practitioners of healing as opposed to ideas of health and the person. She postulates that criticism of the medical model centres on the oversimplification of complex biological disease as well as the host (or body) processes and interactions, that is, in defining health as the absence of disease. However, Sartorius (2006) points out caveats to this definition, including those who do not appear to have physiological problems but feel ill and cannot perform their usual functions to their usual capabilities, which is the case for participants for whom CO exposure and aftermath was not recognised. This would also include the complex issues of Bookie's feelings of not being able to recover from the grief of losing his mother and Matt's own recognition of his diminished emotional responses.

Shah and Mountain (2007) cite various definitions of the medical model that are relevant to mental health issues. These allude to a *"caricature"* (p.375) of a mechanistic and reductionist approach in which doctors are authoritative and can repair a diseased body *"like engineers"* (Nettleton, 2013, p.2) and laypersons are submissive. Discussions of mental and psychological health are pertinent here as both CO exposure and trauma cause symptoms and sequelae that relate to mental health disorders, and some participants were thought to be suffering from mental health disorders in the absence of any physiological explanation for their symptoms (Prockop and Chichkova, 2007;

Roderique et al., 2015). Bookie, Tisha and Ajay also discussed mental health symptoms as a part of the aftermath. Be, Sarah and Kate experienced symptoms such as depression and anxiety, and Be was diagnosed with mental health disorders. Schildkrout (2014) argues that there are many – she describes more than 70 – conditions that are physiological in origin but produce symptoms such as anxiety, hallucinations, psychotic thinking and depression as their dominant indicators. Johnstone (2017) asserts that diagnosing disease in the case of mental health conditions, that is, without physiological, quantifiable indicators such as biomarkers (Strimbu and Tavel, 2011) leads to questions about the understanding of the *"forms of human suffering"* (Johnstone, 2017 p.31) that comprise mental health disorders and whether such conditions can be viewed as disease processes at all. Blaxter (2010) also considers that while acute diseases, or temporary episodes of ill-health, can function well within the medical model, it is more difficult for chronic or contested conditions to be considered in this way.

A lens through which to explore the concept of illness is Parsons's sick role (Parsons, 1951; Fawcett, 2017). When disease is present, people can adopt a 'sick role' whereby they can behave in a sanctioned, deviant manner and are therefore excused from the typical roles that they are usually expected to perform. This allows for the non-fulfilment of usual obligations, as the person is too sick to perform them; in some cases, society may provide for them if they are unable to provide for themselves (Fox, 2012). Kleinman (1978) utilises the term 'sickness' to indicate the response made by others to a person suffering from a disease. It can be seen that this *"legitimated state"* could be attractive due to its benefits and *"potentially mediated secondary gains"* (Bass and Halligan 2014, p.1432). The power of the doctor or healthcare professional legitimises the sickness and is part of the process that enables sick people to return to their usual roles (McKevitt and Morgan, 1997). Difficulties may arise in the case of an individual who is ill, but who does not have a recognised disease or condition, as is the case for many participants here; illness must be confirmed by a medical professional, and the sick individual must conform to appropriately prescribed medical treatment (Nettleton, 2013). As her exposure was unrecognised, Sarah felt unable to take time off work; she appreciated that *"you can't go off sick, with no diagnosis"* (line 123), while neither Be nor Lizzie accepted their misdiagnoses. Other problems arose for participants as their vague and non-specific symptoms were not correctly identified at the time of exposure and during the aftermath. Bass and Halligan (2014) stipulate that physical symptoms are more likely to be considered as legitimate access to a sick role than are psychological or emotional ones, due to a juxtaposition of symptoms being considered as a 'real' disease or a psychosomatic one (Collins and Pinch, 2005).

## Power, justice and judgement

As stated, all participants in both groups contributed to the key theme of power, justice and judgement. Power is an important consideration in this discussion. Power here is often situated with healthcare professionals who largely do not understand CO exposure; this is a feature of the experiences of participants in both groups. A healthcare professional without sufficient knowledge of CO generally lacks power to help anyone living with the impact of exposure. This predicament is situated within the context of objective, medical model thinking that may impose health states on laypersons, rather than accepting the layperson's own experience as valuable (Dean et al., 2017).

The juxtaposition of the experience of those who had MRI or CT scans of the brain is a noteworthy example of such structural medical power (Illich, 1976; Thompson, 2007) here. Tisha had a seizure during exposure and she has lesions present in her brain's white matter, which are visible on MRI and which are attributed to causing her memory and concentration problems (Katirci et al., 2011; Hopkins et al. 2006) and hyperacusis (Roper-Hall et al., 2018). It is, obviously, not known what would have happened had she presented with the symptoms and not had the MRI scan. However, to have damage 'confirmed' as 'official' by physiological testing means there is a subtle difference in how this situation is perceived by Tisha and those around her. She has confirmed brain damage from her CO exposure and her memory issues and hyperacusis are attributed to be the results of that damage; the MRI has validated the damage perhaps more than her own testimony alone could have done. She could, therefore, legitimately operate under the sick role (Parsons, 1951) as a person with a legitimate illness who could be excused from her normal duties.

In comparison, Kate has substantial and burdensome neurological issues in the form of memory and organisation problems as well as agnosia alexia. While she has recovered from the depression that led to her contemplating suicide, she still strives to overcome the aforementioned issues. However, her scans have not shown damage, and she was told by a neurologist that CT and MRI scans would not be able to identify the *"minute"* (line 1967) levels of damage that she, in his opinion, clearly had. However, Kate's Kendrick test, considered to be effective in discerning dementia in older adults as part of a series of assessments (Morris et al., 2000), showed objective damage to her working memory, which for her remains substantial and onerous. It is unclear what difference a positive presence of damage on a brain scan would make to Kate's situation. She has secured a new career despite these problems, so does not at this time need to adopt a sick role with regards to being capable of providing for herself (Fox, 2012). However, validation of the damage she has suffered would, perhaps, have benefitted Kate emotionally. In addition, she still suffers from burdensome symptoms, and does not know what the future holds in terms of her health. Healthcare professionals' reliance on this form of thinking has not, therefore, substantially helped either of these participants. Tisha is a young, previously healthy woman; she wants to further her career and fulfil her normal duties. Kate, despite her successes, may benefit from more support, but does not have a great deal of 'evidence' that she is, indeed, ill.

Although power itself is a neutral concept (Goodyear-Smith and Buetow, 2001), it is a constructive force (Abildsnes, 2012) which can be abused (deliberately) or misused (unintentionally) (Thompson, 2007). It is an *"inescapable aspect of all interpersonal relationships"* (Goodyear-Smith and Buetow 2001, p.500). It is also deemed an unequal yet inevitable part of the relationship between layperson and healthcare professional (Abildsnes, 2012), as one party is seeking help and the other has the relevant knowledge to help them (McKevitt and Morgan, 1997).

Discourse, which in this context refers to the interaction between language and social relationships as well as language itself, is where dominance can be attained by some groups over others (Hugman, 1991, cited in Thompson, 2007). Discourses contain certain rules that align closely with power systems as power and language are linked, with power producing knowledge and knowledge providing power (Abildsnes, 2012). A medical discourse would include influential concepts such as *"doctor's orders"* (Thompson, 2007 p.5) which describes the requirement of laypersons to behave as their healthcare professional tells them to, although there is no formal obligation to do so. The hierarchical nature of this relationship therefore needs consideration here; an asymmetrical distribution of power means a potential for the layperson to be empowered or harmed during the course of the relationship, with Zola (1972, cited in McKevitt and Morgan, 1997) suggesting that such power helps to further the interests of healthcare professionals as a professional group and operates as an *"institution of repressive social control"* (McKevitt and Morgan, p.646). This dominant position is reinforced by and functions in accordance with the medical model way of thinking (Thompson, 2007) and a *"paternalistic assessment by the clinician of 'what is best for the patient'"* (Dean et al., 2017, p.700, authors' punctuation). However, Ahrens (2006) discusses the power dynamics that affect the concept of voice when she says that the means to express oneself are as important as the ability and the right to do so. While the participants were eloquent and became knowledgeable about CO exposure, they were not consistently heard by healthcare professionals. The organisational frameworks of healthcare systems are geared towards the needs of the organisation, rather than the layperson (ibid).

Despite attempts at a more layperson-centred approach (Dean et al., 2017), the paternalistic attitude positions the doctor-as-agent, and is at an extreme end of a spectrum of doctor-layperson relationship; informed decision-making, where the doctor only offers information to the layperson, forms the opposite end of that spectrum (Goodyear-Smith and Buetow, 2001). At the first extreme of the dynamic spectrum, those seeking help from healthcare professionals become passive laypersons (Fawcett, 2017) in a form of parent/child relationship (Fox, 2012). This is a matter of medical authority, or what Illich (1976, p.133) would term as *"cultural iatrogenesis"*; when medical practice is so dominant that it *"saps the will of the people to suffer their reality"* (ibid). The sick role relationship can only operate successfully when due deference is paid to the doctor's medical authority (Parsons, 1951), and it has long been considered that failure to adopt the sick role may result in poorer care (McKevitt and Morgan, 1997).

Paternalistic attitudes may encourage dependency or passivity and can be problematic for individuals who lose some of their ability to attend to their own health and to cope with their own problems (Illich, 1976). Status and power are then attributed to those experts who can define who is healthy (Illich, 1976; Sartorius, 2006). Healthcare professionals wish to support people, but in situations where they have little knowledge, elitism can lead to resentment and lack of co-operation (Thompson, 2007). Healthcare professionals' lack of knowledge is described as a *"touchy subject"* by Wilkesmann (2016 p.430), where ignorance is a neglected topic.

Those receiving help from healthcare professionals can be seen, therefore, as somehow inadequate and lacking in power (Thompson, 2007) but this does not necessarily mean that any oppression, or abuse or misuse of power is taking place. Indeed, as stated, medical power is *"necessary to the medical encounter"* (McKevitt and Morgan, 1997 p.646). When a layperson trusts their doctor, they are confident that the doctor is knowledgeable and will use their power for the benefit of their health (Abildsnes, 2012). Being powerful, or having power, is not automatically equated with being an oppressor (Goodyear-Smith and Buetow, 2001).

Here, issues around voice and not being heard are relevant; social structures – including the healthcare system – *"privilege some voices while excluding others"* (Ahrens, 2006 p.263). Relationships between healthcare professionals and laypersons may be complex (Shah and Mountain, 2007), and discussions about the effects of where power sits in a relationship between the healthcare professional and the individual can be seen as an oversimplification. There are many more factors than just the physiological to be considered in healthcare and healing; there are thus far more complexities at play than, for instance, a mechanic tending to a broken machine (Collins and Pinch, 2005). Healthcare professionals can themselves experience powerlessness if laypersons' interpretation of symptoms differ from their own. They can also *"feel uneasy"* (Gilje et al., 2008 p.37) when their laypersons' symptoms and history do not align with the familiar medical model framework. The layperson can ignore or oppose any proposals or diagnoses made by healthcare professionals. In such cases, the latter perhaps show some consternation at the prospect of an *"expert patient"* (Fox, 2012 p.151): Abildsnes, as a GP, writes *"unbalanced patient autonomy may bracket the GP's contribution to enhance a patient's health"* (2012 p.164).

## Layperson voices

As previously seen with the issues of scan results, the importance that healthcare professionals can tend to attach to diagnosis and treatment – as well as to following medical model thinking – can be inadequate for understanding the layperson's point of view, or of the impact of their condition on their daily life (Dean et al., 2017). Although Vivienne received mainly excellent care, he brought his own knowledge to the situation; he knew that *"physiotherapy, the more you do quickly, the better your end result is"* (line 774) and described the *"official attitude"* (line 2477) towards the lack of physiotherapy he received in the hospital as a *"massive disappointment*" (ibid) and *"the opposite of what it should be"* (line 2478). He perceived his GP practice as not really knowing what actions to take in terms of his crucial rehabilitation once he was discharged, but did not expect them to have a great deal of knowledge about CO, which, like Kate and Curstaidh, he sees as a more specialist subject. He also discussed his rehabilitation as being much improved by the actions that he, again, took himself; he *"nagged"* (line 768) for more physiotherapy and paid for some himself. Vivienne's stay at the treatment centre that he himself arranged was most beneficial.

Be, Lizzie, Matt, Kate, Showgirl and Sarah experienced a lack of regard for their voices when consulting healthcare professionals. Before exposure to CO was recognised, Be was thought to have a mental health problem and the family's issues were all ascribed to this. Lizzie and Sarah had diagnoses of pre-existing conditions. All of Lizzie's efforts to be heard were fruitless as it was just thought to be a part of her condition, which was, in her case, an incorrect diagnosis. Sarah found that her views were disregarded as her symptoms were non-specific and there was no evidence in the form of any biomarkers to explain them. As already established and according to medical model thinking, healthcare professionals have in the past been trained to consider the 'body' before the 'person', and treat persons as *"passive objects"* (Nettleton, 2013 p.5) rather than people with their own knowledge and concerns.

However, formerly passive recipients of healthcare are now changing into *"discrete actors"* (Petersen, 2018 p.130), espousing shared decision-making and a far more participatory approach with and between healthcare professionals. Behaviours and expectations are not passive – the healthcare professional has to advise the best-evidenced intervention, but the person has to choose to act on that advice, whilst coping with the context of their daily lives and their emotional response to illness and treatment.

Being dismissed by having a confrontational, incorrect or even accusatorial meaning imposed on an individual's symptoms can, of itself, cause substantial mental and emotional distress (Thompson, 2019; Laing, 2016) and does not recognise the right of the person to be heard. These participants were not heard; silence is said to be representative of powerlessness (Ahrens, 2016). The layperson or participant voice, when heard, can redress this power dynamic and veer away from medical practice and treatment being centred around medical model thinking (Armstrong, 1995). Recovering from or managing an illness is an active, often iterative process, rather than one that has individuals conferring all power to a trusted healthcare professional through seeking their help. Individuals can choose to connect with, or not participate in their treatment (Shah and Mountain, 2007), with an estimated 50% of people not adhering to their medication schedules for myriad reasons (Brown and Bussell, 2011), leading to increased mortality, illness and financial issues (Serper et al., 2013).

Vivienne's experience of requesting and gaining more physiotherapy represents some meeting ground between layperson and healthcare professional, but Be, Lizzie, Matt and Sarah endured frustrating consultations with healthcare professionals, as their voices were not heard. However, certain changes continue to allow for the possibility for people to proactively develop their own health management. This includes issues such as societal shifts, which have gradually but steadily increased the power and autonomy of people (Illich, 1976; Mockford et al., 2012), including the legislative right of individuals to be involved in all decisions about their own healthcare (NICE, 2019) and advances in information technology (Blaxter, 2010); this has resulted in a reduction of healthcare professionals' control of technical research and knowledge (Goodyear-Smith and Buetow, 2001; Abildsnes, 2012). These shifts in hearing laypersons' voices and concomitant increases in autonomy have been welcomed by healthcare professionals themselves as they bring discernible benefits to laypersons and a reduction in healthcare costs (Dean et al., 2017; Fahey and NicLiam, 2014). This positioning of the laypersons' experience as the source of expert knowledge relates closely to IPA itself, with its focus on close engagement with people's sense-making of their lived experience (Rostill-Brookes et al., 2014). Resnick et al.'s (2004) research illustrates how knowledge of a person's own condition from their own perspective is an important part of the recovery process. Street and Haidet (2010) also state that healthcare professionals have a better understanding of individual experience when laypersons are more active participants in their healthcare. This subject of the relationship between layperson and healthcare professional remains, therefore, complex; although important and less disregarded than before, the layperson voice is not the only voice (Dean et al., 2017) and multifaceted issues abound in doctor/layperson encounters.

## Relationships between healthcare professionals and participants

Curstaidh, for instance, who reported generally good relationships with her GPs, was diagnosed with a chest infection as that is what her immediate, physical symptoms suggested, while her son was treated for migraine for the same reason. Curstaidh and her son were treated for different, common ailments in a way that seems perfectly reasonable to Curstaidh herself; GPs were treating their physical symptoms and not asking about the environment. These 'disorders' did not, however, respond as anticipated to the treatment that should have helped alleviate their symptoms. Since the wrong diagnoses were assumed, the prescribed treatment was not appropriate. This is mirrored in the experience of other participants. For example, Kate's son was treated as though he was avoiding school through feigning stomach ache or headache. Although she took him to the GP on several occasions, he was never referred for investigation of his symptoms. If her GP had not been so sure that there was no underlying physiological problem, some investigations may have taken place, but again, the technology would only have proven useful if the right tests had been ordered, which would have relied on the knowledge of that GP. Heneghan et al. (2009) contend that diagnostic reasoning is commensurate with hypothetico-deductive reasoning. They suggest that healthcare professionals form a diagnostic hypothesis early in a consultation which then directs the rest of the time the layperson and healthcare professional spend with each other, with history and examination used to confirm the healthcare professional's thinking, meaning investigations may be ordered to confirm or exclude a diagnosis. This has clear parallels with medical model, scientific classification thinking.

An example of this concept may be Sarah's meeting with the consultant who seemed to object to her active participation in her own healthcare, despite the presence of the notes that Sarah had brought from a previous consultation to support what she was trying to communicate to him; namely, that she had been managing the condition well but was deteriorating. To him, she did not fit the profile of her previous diagnosis so he rejected that diagnosis out of hand without considering the evidence she had brought and without confirmatory or new investigations. The result of the encounter was not conducive to identifying the cause of Sarah's worsening symptoms as CO exposure, as this consultant became *"aggressive"* and *"he actually got shouty on me"* (line 1012). Sarah felt that her safety was being compromised, and called a friend who was in the hospital to help her. This represents the disturbing degree to which Sarah's proactive attitude posed a threat to this consultant.

As discussed, high status has been given to doctors due to their expert knowledge (Illich, 1976). Pietikainen (2015) discusses diagnosis as an exercise in expert power that can influence a person's self-understanding, however caring or compassionate the motives for doing so. Kleinman (2013) believes, however, that healthcare and its training are themselves structural barriers to caregiving, and there are distinctions between healthcare and what laypersons who are not healthy require. Verghese (2008 p. 2749) criticises the healthcare trainee's experience of having more to do with the *"iPatient"*, that is, a person's results from scans, laboratory testing and diagnoses, than with the actual patient themselves. Kleinman (2013) states that his original ideas about the importance of laypersons' lived experience of illness and its place in doctor-layperson interactions (Kleinman 1988) as something to transform *"a one-sided interaction into a richer, more egalitarian one"* (Kleinman 2013, p.1376) have not materialised. Instead, he feels that interaction has become merely another *"mechanical"* (ibid), task-oriented, perfunctory routine performed on laypersons by doctors without necessitating much input from the layperson. This can be seen often in the participants' experiences, with Matt's missed diagnosis and later rejection of his own ideas about the cause of his sequelae, and several participants' long histories of fruitless, discouraging GP appointments and A&E attendances. It seems that once the iPatient's issues have been addressed, the actual layperson does not have any power to alter the doctors' ideas.

## Justice

In attempts to redress the balance of power between themselves and the responsible agencies, Bookie and Kate were part of successful court cases that granted them compensatory justice for the negligence of the companies who caused their CO exposure. Both said that they did not want the money, and that it did not help them to feel as though they had received justice for their suffering, which both continue to endure. Bookie's court case was between the Health and Safety Executive and the company, further removing him from any position of autonomy; although he wanted the head of the company pursuing, this situation afforded him less power than he otherwise would have had during the protracted court proceedings.

Following the 9/11 terrorist attacks in the US, explanations for tardy application to the Government compensation fund included the complicated procedure for application, belief that the process would be intrinsically unfair, that is, issues of power would not be redressed equitably, and the difficulty of rendering *"personal devastations into actuarial calculations"* (Tyler and Thorsidottir, 2003 p.356). Potential applicants also felt that it was a *"shut up Fund"* (sic) (ibid) or a whitewash, designed to conceal and conclude a challenging issue. These sentiments were all echoed by Bookie and Kate. Neither felt that they had really achieved justice, that any power issues had been redressed, nor that any amount of money could represent compensation for what they had endured. Curstaidh echoed this opinion; although she did not, eventually, seek court, she was told it would be exceedingly difficult to translate her and her son's suffering into monetary recompense.

Tisha and Ajay's experience of speaking with lawyers led them to use words such as *"cut-throat"* (lines 677 and 1791) and *"aggressive"* (line 676). Relis (2007) argues that many lawyers see monetary gain as the primary objective and do not consider that the legal system can provide anything more than that for the people they represent. Lizzie considered legal action but there was, in her situation, no case to answer. Sarah and Be were seeking routes by which they could gain justice at the time of their interviews. All of these participants were clear that their actions were not solely (if at all) motivated by the desire for money. Relis (2007) discusses a similar situation in her review of plaintiff litigation aims, where people had more concerns about prevention of occurrence, admission of fault and acknowledgement of harm. Bookie felt that he was unable to accept or recover from the death of his mother due to its injustice; Relis' (2007) findings around bringing the perpetrator to justice are relevant here, as the owner of the company which Bookie took to court is a wealthy, powerful individual who closed down his current companies and set up new ones: *"they* *just go bump and set up again! […] He'll be still trading, this guy [..] under some other name"* (line 1748).

## The experience of being an invisible woman with CO exposure

Some findings discussed the gendered aspects of the CO experience; this is related to how they were positioned in the power dynamics of healthcare professional and layperson, and I discuss them here as another extrinsic aspect of the experience. Be, Sarah, and Lizzie in particular felt that they were not heard. As well as the reasons for this possibly including the elusive nature of CO exposure recognition and diagnosis, especially at lower concentrations, these participants felt that they were not heard *because* they were women. Women in particular are more likely to suffer with ambiguous or contested illnesses (Johnson and Johnson, 2006), present to healthcare professionals with *"unexplained"* disorders (Malterud, 1999 p.197) and have different expectations and experiences of healthcare due to their gender. Questioning healthcare professionals' dismissal of their symptoms and sequelae led to castigation. *"Crazy women"* have transgressed in some way, and by trying to proffer an explanation for something, they have attempted to alter the power balance that exists in relationships like that of doctor and layperson. This term, that Sarah, Be and Lizzie used, shows invalidation of their opinion, as well as their symptoms, and does not allow them a voice (Ahrens, 2006). This entails complex societal factors beyond the scope of both this work and its examinations of the doctor/layperson relationship, but I engage some of the pertinent issues for these women here.

Firstly, there are some suppositions concerning gender and healthcare that are germane to this discussion. While men and boys are 'expected' to be tough, tolerating pain and illness, women and girls are socialised to be *"sensitive, careful, and verbalise discomfort"* (Samulowitz et al., 2018). While Hunt et al. (2011) postulate that evidence for the assumption that women consult healthcare professionals more than men is weak and inconsistent, Ussher (2018) affirms the gender bias inherent in the medical model, with women more likely than men to be diagnosed with mental health disorders throughout history, and more likely to be given *"potentially stigmatising labels"* (Ussher 2018, p.76) such as Premenstrual Dysphoric Disorder (PMDD). Women who are ill, as well as operating within a sick role, are expected to continue with their usual roles of caring and nurturing. Not doing so can bring their *"womanliness"* (Malterud, 1999 p.16) into question. Women entering into consultations with their healthcare professionals expect that their concerns will be taken seriously, and they will receive help and support for their symptoms (Ahrens, 2006; Laing, 2016), but another notion is that women may lack capacity for rational decision-making about their own healthcare when compared to men (Abrams, 2015). Therefore, they may find that they are ignored and their opinions disregarded, with any explanations they offer around their own health rejected. Malterud (1999) also discusses pleading, crying and begging during consultations with healthcare professionals in the face of continued resistance to listening to their concerns. Sarah, Lizzie and Be all give examples of this desperation in their accounts. Ultimately, this treatment spurred these participants to seek their own remedies as active users of healthcare who now have a deep understanding of CO exposure.

There is, unfortunately, a strong precedent for Be, Sarah and Lizzie's experience of not being listened to in healthcare due to their gender. As stated, Kurtz et al. (2008 p.55) consider the silencing of the voice to be *"an act of structural violence"*; a concept whereby social structures result in further marginalisation of the individual and their concerns (Ahrens, 2006). I will illustrate this using brief examples of conditions that are also not straightforward in their diagnosis and management, especially with regards to gender. Firstly, pain is a subjective symptom, for which often a cause remains elusive. Endometriosis is a further example of women's lack of voice in healthcare, as a long-neglected and untreated condition.

In an influential study of women's pain, Hoffman and Tarizan (2001) discuss women's under-treatment of pain when compared to men's treatment. The reasons given for this vary widely, from men's comparative stoicism – with the result that when they do complain about their pain, *"it's real"* (p.13) to women’s inaccurate reporting of their symptoms, or even women’s higher tolerance of pain. The subjective nature of pain and, often, the concomitant lack of evidence for its existence, is cognizant with these participants’ experience of CO exposure. While various aspects of prejudice, such as class and race, affect healthcare professional and layperson interactions, gender is said to be especially influential (Aboulafia, 2019).

In the UK, NICE’s first quality standards and guidance on endometriosis, which affects one in up to every 10 women (Nnoaham et al., 2011), were published in 2017 (NICE, 2017). Previously, guidance had been available only as part of the general guidance on fertility (NICE, 2017a). Most relevant to the discussion here, doctors and healthcare professionals are encouraged to listen to sufferers, work with them, and not dismiss their symptoms even if ultrasound scans, blood tests and MRIs are negative.

Affected people can wait, on average, 10.4 years between onset of symptoms and a diagnosis of endometriosis (Hudelist et al., 2012). One reason for this delay is the normalisation of symptoms, that is, sufferers are told that there is nothing abnormal about what they are experiencing, just as Kate was told that it was normal behaviour for her child to feign illness to avoid school. Be, Sarah and Lizzie felt that their concerns were not listened to and that their health symptoms were discounted and doubted as being ‘real’. Kurtz et al. (2008) assert that when ignored, women risk far poorer outcomes and eventually disengage from healthcare services, as Be and Sarah have done.

It is postulated that women struggle against the diagnosis of mental health disorder when they have non-specific symptoms and do not have an objective diagnosis (Kleinman, 1994) and report not being taken seriously by healthcare professionals (Kiesel, 2017; Kleinman, 1994). This and lack of knowledge from healthcare professionals leads to feelings of frustration and despair for participants here and in other literature (Wehbe-Alamah et al., 2012). Those who suffer symptoms with no objective results risk lack of acknowledgment and inappropriate care (Malterud, 1999), as happened here.

## A divergent theme: Being *"accused"* of being a *"Munchausen's mother"* (Be, line 2281)

However, Be's experience of being *"accused"* (line 754) of being a *"Munchausen's mother"* (line 2281), of having the rare medical condition MSBP, has had a devastating effect on her (Hoyle and Burnett, 2016). This word, and her naming of the condition as MSBP rather than the more contemporary Fabricated or Induced Illness (NHS, 2016) or Factitious Disease(s) in the DSM-V (Pacurar et al., 2015), suggests that the harmful language of caregiver-as-perpetrator of abuse endures (Bass and Glaser, 2014) and is a cause of acute distress to Be. Unal et al (2017)'s case study argue that such disorders are still classed as medical abuse. Factitious Diseases are rare, challenging and difficult to diagnose conditions (Savino and Fordtran, 2006; Lauwers et al., 2009); again, there is a dearth of literature from the perspective of the sufferers of this disorder. Factitious diseases are also frightening. Healthcare professionals are committed to caring for laypersons; it is difficult for them, and for the public, to think of harm being caused to a most vulnerable layperson, by a mother, to the point where a child endures a great deal of suffering and could potentially die (Castiglia, 1995). It is beyond the scope of this work to explore the criteria for a diagnosis of a factitious disease, or inducing harm, which remain contested (Bass and Glaser, 2014); evidenced from her account, Be does not meet them. However, Be was terrified by the *"threat"* (line 1984) of social services becoming involved as she perceived that her children could be removed from her care if the ideas that she was inducing illnesses perpetuated, despite her protestations that her children were genuinely ill. Be actually had the antithesis of a factitious disease, as she, her husband and her children were suffering from various non-specific symptoms that were caused by their CO exposure; they had a hidden, undiagnosed but very real 'disease'. Similar situations have been reported of parents being wrongly accused (Dyer, 2006), but the incidence of how often parents are falsely 'accused' of causing symptoms in their children is unidentified. If more were known about CO, and in this case, factitious diseases, this distressing aspect of her situation might have been avoided for Be.

There are social expectations of ‘good’ and ‘bad’ motherhood; good motherhood is fundamental to expectations of femininity (Frederick, 2015). Stigma is therefore attached to the ’bad’ motherhood where mothers do not conform to societal ideals and children are deemed to be not cared for adequately. Ideas persist of motherhood being biological in aspect, and nurturing is therefore an inevitable role for women (Abrams, 2015). An example of this can be seen above, in the previous inclusion of endometriosis, which is a debilitating, common medical condition, only in general fertility advice until very recently (NICE, 2017a) – as though it is a condition that only matters to those trying to conceive.

Be often felt herself to be judged as a bad mother. An example of this concerns gender roles and lack of recognition of the real cause of the problems: her youngest daughter’s severe behavioural problems would disappear when she was staying at her grandparent’s and, of course, away from the source of CO exposure. Without recognition of the effects of CO, this was thought, even by her family, to be due to Be’s parenting.

Again, gender and the language used around gender is an issue. In most cases of this little-understood, contested disease, the mother in a heterosexual couple is the caregiver responsible for the harm to the child. Some fathers suffer with the disorder and there are some older adults who have been victims (Zylstra et al., 2000). The proportions are estimated at 76% biological mother to 7% biological father (Sheridan, 2003). Where fathers cause the harm, mothers appear to *“allow the abuse to continue”* due to their *“weakness, inadequacy, passivity, or unloving nature”* Meadow (1998 p.215). This is juxtaposed with remarks about *“uninvolved”* (Bass and Glaser, 2014 p.1414; Castiglia 1995 p.75) and *“truly unaware”* (Bass and Glaser 2014, ibid) fathers.

Allison and Roberts (1998) are among authors who contend that fabricated disorders or diseases may not exist, which is not to say that there is any denial that parents abuse their children. They discuss recursivity when describing earlier work on Munchausen’s Syndrome, stating that the syndrome was identified in laypersons because they presented to healthcare professionals displaying the same symptoms as the only other person known to have Munchausen's syndrome, and thus they too must have the same condition. As with Munchausen's syndrome, factitious disorders involving the harm of others are very difficult to study as sufferers do not often consent to assessment and/or treatment (Fisher and Mitchell, 1995). Allison and Roberts (1998) discuss an *"affabulated aetiology"* (p.277) and contend that the MSBP *"abuser/mother"* (ibid) is treated and punished as an exceptionally appalling abuser of her own children.

## Stigma and illness

As also discovered by some participants, in particular Be and Lizzie, and to a lesser extent, Sarah and Matt, once the label of having a mental health disorder is present, people's ability to make their own decisions is questioned. Any concerns that they express, whether about themselves or their families, are merely considered to be another manifestation of that disorder, with feelings of being patronised or humiliated when encountering the healthcare professionals that are supporting them (Thornicroft, 2003). This led to lowered esteem and hope, and feelings of negativity for those participants (Thompson, 2019), and despair when they thought that there would never be any recognition for their concerns. As discussed, defining an individual in this way, by giving them a label or a diagnosis, is an exercise of power (Pietikanen, 2015); stigma in such settings is not merely, therefore, a question of someone with a specific characteristic who is in need of medical treatment of some sort, but rather, it has wider-ranging social and political implications. As an example, Briant et al. (2013) discuss the lessening sympathy in tone found in newspapers reporting on disability after austerity measures were implemented in 2010 in the UK. Vivienne was given an opportunity to identify himself as someone with a disability but did not do so; while he may have had many other reasons for doing so, he stated that he did not because he considered that the label of disability could potentially negatively impact his working life, leaving him with less autonomy.

The concept of stigma is closely related here to the previous sections on power and the lack of power faced by the participants. Stigma explores how people can become marginalised (Frederick, 2015), and it operates within the hegemonic ideas of the dominant culture (Abrams, 2015; Thompson, 2019), which labels and stereotypes unwelcome behaviour. Stigma is an extrinsic force that negatively affects those stigmatised in terms of their social identities, and is destructive and damaging (Thompson, 2018), particularly in the case of chronic illness (Engebretson, 2012), causing psychological harm and physiological stress responses (Telford et al., 2006; Abrams, 2015). Stigmatized people suffer with low social status, negative self-perceptions and problems with emotional wellbeing (Link et al., 1997). Stigma definitions concern a characteristic that identifies someone marked (Thompson, 2019) as different or 'other' and that characteristic is then accepted as a social construct (Abrams, 2015). The particular characteristic signifies something undesirable, discrediting and weak about that person, creating an incongruity between the individual and their social identity, and the identity that is perceived by others (Goffman, 1990).

Stigma is reinforced by negative stereotypes (Thompson, 2019) and gender stereotypes (Abrams, 2015). Stereotypes about disability (Frederick, 2015) also play a role in the creation of stigma. While many forms of disease-related stigma persist (Telford et al., 2006), Thompson (2019) also suggests that stigma specifically about mental health forms a part of *"mental health mythology"* (p. 23) that arose due to the misconceptions of the anxious public. Again, the identity of the sufferer is perceived by others and affected by those ideas. The media also plays a part in health mythology; Clarke and Everest (2006) describe frequent metaphors of 'battle' and 'war' in reports of cancer.

Stigma persists for unrecognised conditions such as CO exposure and the symptoms of its aftermath, as these non-specific symptoms suggest to healthcare professionals that the person may not be truly ill, meaning that they are malingering, fabricating, or have mental health problems, and the reductionist medical model does not apply. Symptoms are seen as not being 'real', and there is no objective evidence, such as in the form of biomarkers, 'proving' the presence of an illness. Fox's (2012) discussion of stigmatisation alludes to the negative value that people hold in the eyes of others when they have conditions such as mental health disorders, HIV and obesity. Frederick (2015) suggests they are so viewed because others perceive them as having at least some responsibility for these conditions, and that this inflicts a *"second burden"* (Fox, 2012, p.160; Knight-Agarwal et al., 2016) on those suffering. This was the experience of many participants in group two, and also of Matt.

The concept of stigma is closely linked to ideas about identity; people accept the construct of stigma about their defined characteristic about themselves, and so stigma becomes internalised (Abrams, 2015). This is also known as self-stigma (McInnis et al., 2014); again, it can result in lowered self-esteem and depression and anxiety. Stigma can also be experienced in other ways. For instance, it is perceived from others' negative attitudes, but it may also be enacted – that is, the individual encounters prejudice or discrimination as a result of the characteristic (Abrams, 2015). This has been demonstrated in healthcare settings (Puhl and Heuer, 2009), where stigma is often linked with rare or vague, contested or ambiguous illnesses (Johnson and Johnson, 2006), such as the experiences of many participants here. Such conditions can be inexplicable in terms of the medical model way of thinking. As such, the potential for stigma exists for both groups of participants, as many in group two did not have CO exposure recognised despite symptoms, and many in both groups are left with sequelae that may be poorly understood.

## <u>Identity in ill-health: Power and stigma</u>

> *"We carry our identity with us through life"* Fox 2012 p.53)

IPA studies allow people to explore and make sense of their experiences, so it is unsurprising that IPA findings are concerned with identity and self. Matters of identity are closely linked with ill-health, especially longer-lasting periods of illness, and as such concern the majority of participants. Many talked of the devastating impact of CO exposure and how their views of their sense of self had altered as a result, to the extent that some participants do not feel that they are the same people that they were beforehand. These experiences are shattering and disruptive, and not considered part of normal existence (Larsson and Grassman, 2012), as, for instance, a congenital condition might be. Participants' experiences of illness and healthcare led to feelings of anger (Medved and Brockmeier, 2008) and regret, as these experiences were out of their control (Charmaz, 1995). This has clear links with the issues of power that form so much of the participants' accounts; their internal perceptions around their own personal power and identity changed because of exposure to CO (Edwards et al., 2014) and the reactions of others. The literature on identity and self following various forms of illness and trauma is wide-ranging; trauma, when overwhelming, involves the violation of the sense of self (Randall and Haskell, 2013). I will therefore discuss it briefly, as it forms an important part of the examination of the aftermath of CO exposure for all participants, whatever their exposure experience.

Charmaz (1995) discusses how ill-health can compromise the *"integrity of self"* (p.657) and undermine self and identity. Kate's forced change of career path and depression were not something that she recognised as being 'her'; she did not identify herself as someone who would usually suffer with depression *"my personality isn't … I'm not a depressive person"* (line 381). Bookie also had to give up his career due to his experience; this is consonant with Rao et al.'s (2009) research on stigma and chronic illness. In addition, as with the participants in Smith and Osborn's (2007) research, many participants experienced identity issues in relation to their dealings with others, emphasising *"the 'socialness'"* of their experience (p.528, authors' punctuation). Bury (1982) states that relationships between those who are chronically ill, their loved ones and their wider social networks are examined *"in stark form"* (p.169) under such circumstances, as usual rules of reciprocated support no longer apply. This is a key aspect of Bury's (1982) biographical disruption. Examples of this are the dealings with healthcare professionals as detailed; Bookie also initially experienced some social isolation when he could no longer work. Being unable to work led to an increased risk of poverty which would have enhanced his social isolation. Be described herself as being *"the most unreliable person"* (line 67) whose friendships and relationships fell apart, in sharp contrast to her previous identity of an organised, competent, highly sociable and capable person.

For many participants, aspects of self emerged from the experience, rather than being something that they ‘fitted’ to their previous notions of self. For example, Showgirl, when discussing her GP’s lack of knowledge about what to do about her CO exposure symptoms that had no physiological proof, identified herself as someone who was usually healthy: *“I’m not in the surgery every five minutes … I’m not a big customer, am I?”* (line 2049-51). Before her experience with CO exposure, she had not experienced trouble with any healthcare professional recognising any health-related condition and so had not experienced the issues that came with having an ambiguous or contested illness. She was clear that she would not, now, accept the diagnosis of chronic fatigue: *“I really don’t want to go down that [.] route [..] … because that’s where you get left”* (line 1561). This was guided by her own knowledge; she did not agree that she would have such intermittent symptoms if she had chronic fatigue, and she feared that those with such diagnoses tend to *“get left”*, which is consonant to Lizzie’s *“dustbin diagnosis”* (line 350). Showgirl also felt that the GP did not know how to help her. Some participants were pragmatic about what they expected from interaction with healthcare professionals, in line with Bury (1982); they realised that knowledge about CO exposure is limited and incomplete and that CO exposure remains elusive.

Like others, such as Lizzie, Be and in particular Sarah, Showgirl felt unwell and fatigued which caused her to seek medical help. None of these participants welcomed a chronic fatigue-type diagnosis. Consistent with this experience, Raine et al. (2004) found that GPs had a tendency to stereotype laypersons with chronic fatigue. Harvey and Wessely (2009) state that GPs felt hopelessness when presented with laypersons complaining of fatigue and thought of them as having certain *“undesirable traits”* (p.1). Chronic fatigue is mentioned by several participants. For example, it was a diagnosis given to Kate’s son in the years following his exposure. Sarah’s neighbour, with whom she shared the loft space (and was therefore also exposed to CO) has a long-standing diagnosis of Myalgic Encephalomyelitis (ME), a condition that is sometimes conflated with Chronic Fatigue Syndrome (Committee on the Diagnostic Criteria for ME/CFS, 2015) and Sarah also recognised that chronic fatigue symptoms have much in common with the CO exposure experienced by herself and other participants.

Agreement on definitions of identity and self, or how an individual defines or represents themselves, remain obscure but are necessarily broad as this is a complex area (Smith and Osborn, 2007). For Fox (2012), identity and selfhood emerge from a myriad of possible identities as an individual develops and experiences different events, thus modifying the identity, formation of which is an *"active, creative process"* (p.78). Sometimes, an experience can so alter an individual that they feel very different from before (Bury, 1982), as happened for many of these participants. The development of a condition, especially if that condition is not readily explicable (Winger et al., 2013) and its presence means an uncertain future for sufferers (Wawrziczny et al., 2016; McInnis et al., 2014), and can fundamentally transform an individual, for example, from an independent to a dependent identity. People can, as considered by Wawrziczny et al. (2016), fluctuate between acceptance of the situation and possible progression of symptoms, accompanied by uncertainty about the future and about how those symptoms will evolve. Kate knows that she has progression of her symptoms; along with Sarah, Showgirl and Vivienne, career is part of her identity (Fox, 2012) and she talked about her frustrations in having to change her career, and her worries about being unable to continue with the new profession if her sequelae continue to progress. Kate has to contend with the frustration of not being able to have any more objective measurement of the progress of her symptoms; as she cannot be treated, her consultants are unwilling to perform any more investigations.

The self and identity are also crucial components of the sense-making process (Armour, 2010). Identity would also be affected by any associated stigma from the circumstances of, for example, CO exposure (Charmaz, 1995; Smith and Osborn, 2007); Goffman (1972) discusses identities that have become stigmatised and thus debased, such as when participants such as Matt and Be had to cope with symptoms or misdiagnoses of mental ill-health due to their exposure. This was a distressing experience, and participants tried to find ways to contend with it. Bookie, for example, deflects a potentially difficult situation when telling people that he is under psychiatric care by making a joke out of it, in order to buffer any stigma: *"I say I'm crazy, I'm mad as- I'm eccentric I'm mad as a hatter, so I go and see my shrink"* (line 1061), thus normalising this behaviour and identifying himself as humourous and therefore non-threatening.

As well as an awareness of a perceived stigma (McInnis et al. 2014) and possibility of malingering (Winger et al., 2013), the diagnosis and course of chronic fatigue over time are unclear, as is the aftermath of exposure to CO. There is also little in the way of biomarkers; both chronic fatigue and CO exposure are a cause of medically unexplained symptoms (Winger et al., 2013). People who present with such symptoms inevitably are sometimes disbelieved and mistrusted by healthcare professionals (Nettleton, 2013; Johnson and Johnson, 2006), as the usual power dynamic, reliant on the expert knowledge of the healthcare professional, does not apply. The condition is easily seen, therefore, as something that *"sits in the head"* (Winger et al., 2013 p.2650) and consequently, as stated, prompts stigma and can also lead to sufferers being discredited as their symptoms are hard to explain; symptoms are present when objective evidence of illness is not (Charmaz, 1983). Mistrust from others, including healthcare professionals and family members, imposes a meaning of its own rather than allowing the person to form their own meaning about the experience, which is important for maintenance of identity (Thompson, 2019). Being disbelieved has been part of the experience for many participants, as part of the elusive nature of CO itself. In the absence of much knowledge about CO and in the absence of carboxyhaemoglobin, the only considered biomarker for CO, many participants' conditions were misunderstood or many were disbelieved, especially for participants in group two, whose non-specific symptoms waxed and waned (Schildkrout, 2104). This is referred to by Kotarba (1983, cited in Smith and Osborn 2007) as *"victim blaming"* (p.529). As Be affirmed, she felt that victim blaming was a pervasive part of her experience and how she was treated over her long exposure. People who are seeking support and validation, and instead encounter victim-blaming attitudes, often feel a sense of betrayal known as secondary victimisation (Laing, 2016). In all, objective diagnosis is vague, as are symptoms.

# The body and identity

Fox (2012) discusses the difficulties of using a medical model to explain illness when the body is actually seen as a source and symbol of identity, where the biology of the body and the social identity of the person together comprise embodiment. This is akin to Merleau-Ponty's (2002) ideas of how people communicate with the world through their bodies, and how any form of ill-health that is not transitory and easily explained by medical science can mean that the body can become unfamiliar (Winger et al., 2013). Experience usually cultivates a sense of self that develops into *"a well-rounded identity"* (Fox 2012, p.53). The reason that Showgirl gave for refusing to accept the diagnosis of chronic fatigue was, therefore, concerned with her identity. She saw herself as someone who could not have chronic fatigue, because of her own knowledge of the condition and because she was not someone who went often to the GP; she was not a *"professional … patient"* (line 1489). Thompson (2019) also considers that medical model thinking, in line with earlier discussions on power, positions the individual as a *"passive victim"* (p.108) who is unable to assert their usual identity. As stated, however, few authors would now claim identity as innate; rather it develops due to experience, the social context in which they take place (Fox, 2012) and the varying nature of the illness or disability itself, which, like CO exposure and its aftermath, is rarely static (Bury, 1982). Thompson (2019) affirms that the thinking of people as having a fixed identity and sense of self is also disempowering.

An aspect of identity that becomes dominant when people are ill, especially if that illness is chronic, is inevitably concerned with health. As seen, healthcare systems often present challenges to people's usual identities (Fox, 2012), replacing them with an over-riding illness identity (Charmaz, 1995). Parsons's sick role (Parsons, 1951), for instance, as previously stated, envisages a dependent, parent-child relationship with the dominant doctor. In an effort to overcome some of the dissatisfaction with this aspect of healthcare, some participants sought their own remedies (see later section). This also allowed them to assert some control over the situation.

It is not inevitable that loss of positive social identity will happen in cases of chronic illness (Cuthbert, 1999, cited in Smith and Osborn, 2007; Bury, 1982). For example, Kate, despite her serious symptoms, and Vivienne, despite his loss of his partner and a life-changing injury, gave clear examples of how they have regained high levels of self-regard and productivity, as did Sarah, Tisha and Ajay. Whilst the cited research discusses the maintenance of these high levels of positive social identity during chronic illness, I feel that many participants have returned to, or regained those levels after they have experienced and then coped with the trauma of CO exposure. This is supported by Medved and Brockmeier (2008). Their participants too suffered neurotrauma, albeit not from CO, but they reported adaptations, but no ultimate loss of former sense of self.

## Connectedness

Social connectedness is closely linked to selfhood and identity (Ja and Jose, 2017; Haslam et al., 2018), with Liao and Wong (2018) discussing the links between gratefulness, wellbeing and social connectedness. Their experiences also led some participants to appreciate the everyday aspects of their lives more than they did previously (Winger et al., 2013). Ajay in particular talked about his felt sense of wonder and new appreciation for life; he and Tisha are both heavily involved in charity work. Such volunteering is known to grant psychological benefits including feelings of meaning in life, lower depression, enhanced social support and integration and improved feelings of wellbeing (Creaven et al., 2018). While I did not know about pre-exposure levels of social connectedness, or particularly explore that with participants, many expressed motivation to be involved in awareness raising and charity work. Social connectedness is therefore maintained for many participants by this charity work, which acts as a form of social support and as such helps them to cope with aspects of their traumatic experience (Thompson, 2019; McDonough et al., 2011). The participants tell their accounts, sometimes many times over, in order that other people might avoid CO exposure, and in doing so, reflect their own ideas about their own self in relation to other people (Lee et al., 2001).

Liao and Wong (2018) also discuss meaning in life, as the *"sense made of, and significance felt regarding, the nature of one's being and existence"* (Steger et al., 2006, p.81, cited in Liao and Wong, p.384) as the underlying mechanism between gratefulness and wellbeing. They mention religious faith as being a predictor of meaning in life. Kate spoke of her belief in things happening for a reason, while Tisha echoed this idea, saying that perhaps the reason she survived was to *"spread the awareness, and [.] do some good, out of it, really"* (Line 708). Fulginiti et al. (2018) state that finding such a purpose through connectedness can alleviate suicidal ideation in youth, so it is entirely possible that the participants helped themselves as well as others through this charitable work.

A history of personal traumatic experiences may increase the likelihood of compassion fatigue when faced with others' accounts of trauma (Adams et al., 2008). However, compassion satisfaction may be protective against compassion fatigue; this results from the positive experience of being able to help others. Crucially, the participants felt believed by those at the charities with whom they dealt, and as such, networks and charitable organisations have been extremely important, positive aspects of some participants' experience: *"without them we would have felt quite isolated"* (Tisha, line 1852). When discussing the  charitable work for CO awareness-raising organisations, the participants told me that connectedness was an important characteristic of the experience and aftermath for them, in some case ameliorating the effects of their trauma.

While little is known about how people's subjective sense of connectedness is formed (Urminsky, 2017), for many participants, meaning regarding the experience was derived from this connectedness to others, which was a source of support and comfort to them. Kate provides a succinct example of this. She believes that *"things happen for a reason, and obviously for me to go through it, is to help other people"* (line 2199). Kate and Tisha and Ajay in particular described the social support and the benefit that they derived from contact with the CO charitable organisations and the awareness-raising work that they now do with those organisations.

However, feelings of being stigmatised were considerable for participants who experienced more social isolation, such as for Bookie, who was unable to work, and Lizzie, through her husband's behaviour, which resulted in Lizzie being isolated. Be felt that the family's friends abandoned them; Showgirl felt that her friends and family just did not comprehend what she was enduring. Be and Lizzie also experienced social isolation with stigma in their dealings with healthcare professionals and other authority figures, as did Sarah. This is similar to the isolation of the participants in Edwards et al.'s study (2014) on acquired brain injury. Saeri et al. (2018) stress the importance of social connectedness; those who lack it or who experience it in a limited way are known to have poorer mental and physical health and die younger. There is disagreement about whether poor social connectedness is a consequence or a cause of mental ill-health, with Oldfield et al. (2018) citing the potential of connectedness to shape, positively, resilience for those who experience trauma.

The need to be connected to others is of crucial importance and *"one of the most basic aspirations of human beings"* (Freeman, 1993 p.3). Connectedness, or social connectedness, is defined as an attribute of the self that reflects perceptions of durable interpersonal closeness with the world as a whole (Lee et al., 2001). It is also an umbrella term concerned with subjective connections to other people. This includes mutual social support and an absence of loneliness, leading to a feeling of belongingness (Saeri et al., 2018). Wayment and Walters (2016) discuss how people flourish when they have human interaction and how perceived social support is *"one of the most powerful predictors of health and well-being"* (p.2115); lower levels of social support are associated with later feelings of bitterness about the situation (Kaniasty, 2012). A sense of connection is meaningfully associated with powerful benefit for individuals, and is at the centre of suicide prevention approaches (Fulginiti et al., 2018).

## **Sharing the experience**

Talking about the experience in the setting of the interview was also helpful for the participants. As well as expressing the thought that this was an extremely important piece of research which would address a neglected and vitally important aspect of knowledge about CO (Lizzie, Kate, Be, Tisha and Bookie), talking about CO exposure allowed for further integration of frightening experiences into their lives (Jensen, 2019). Jensen (ibid) and Ladegaard (2015) both discuss the retelling of traumatic events, and how the tellers themselves are aware of issues like incomplete and disconnected, even inconsistent details, and: *"the fragility of this narrative representation of a physical, emotional and psychological experience"* (Jensen, 2019, p.29). Transforming traumatic experiences into narrative is seen as a common therapeutic tool which can be both empowering and positive (Tuval-Mashiach et al., 2018; Wagstaff et al., 2014). While research interviews are given to provide data, as discussed, I was surprised at this aspect of meeting the participants, who were grateful that the work was happening and felt that their participation was a part of raising awareness, as well as finding it personally beneficial. Richards and Emslie (2000) discuss this aspect of research interviews, saying that some of their participants relished the opportunity to discuss their experiences in detail, with someone who believed them. As echoed by participants here, talking to a researcher was *"cathartic"* (p.72); they likened their interviews to a session with a psychiatrist. Jensen (2019) cites Blackwell (1988) when discussing the benefits of using narrative in therapy. The epistemological position that supports this approach is, according to Blackwell (ibid) is one of social constructionism (Denzin and Lincoln, 2013; Polkinghorne, 1992) where the narrator (in this case, the participant) draws meaning from interactions with the environment (Smith, 1996; Thompson, 2019), which is, in this case, the context of the meeting with me.

## Making (and missing) the difficult diagnosis of CO exposure

I now turn the discussion to CO as it is discussed in the literature, in light of both the experiences of the participants with regards to the effects of exposure and the previous discussions on health, healthcare and power. I argue that the symptoms and sequelae that were discussed by the participants both shared commonalities with and problematized the studies presented in chapter two (Smith et al., 2009). Many health conditions remain medically unexplained (Gilje et al., 2008);

the origin cannot be found, nor can a diagnostic test using a biomarker be utilised. This is true of CO; although the mechanisms of CO exposure are partially understood, the presentation and course of CO exposure are highly variable (Wolf et al., 2017; Abdulaziz et al., 2012), and diagnosis of CO exposure is itself far from straightforward (Buschelli Ramirez, 2014). I would argue, however, that the difficulties of diagnosis are complicated by the levels of knowledge about CO. Table 13 summarises the issues that participants encountered in their communications with healthcare professionals that reflect what those healthcare professionals appear to understand about CO exposure.

## Table 13: Healthcare professionals' knowledge of CO exposure, as perceived by participants

| **Knowledge** | **Experience** |
|---|---|
| 1. Acute exposure (higher concentrations of CO, usually over a shorter period of time) is the important issue | - Chronic exposure (lower concentrations of CO, usually over a longer period of time) was the concerning issue for those in group two |
| 2. *"It [CO] either kills you, or it doesn't"* (Lizzie, line 220)<br>*Recovery from CO exposure, should one survive, is relatively straightforward and invariably complete* | - All concentrations of CO exposure, may lead to diverse and persistent symptoms/reasons for developing these symptoms are not always clear<br>- These symptoms may appear some time after exposure has ceased, perhaps with the individual feeling well in the interim |
| 3. Oxygen starvation of tissues (hypoxia) is the cause of symptoms<br>*While hypoxia is a critical and damaging element of exposure, a logical conclusion to this statement is that once CO is no longer being inhaled, harm stops occurring to the body and brain; once the individual starts to recover from hypoxia, overall recovery will commence and progress. This is not the case and is not reflected in the literature (for example, Hopkins et al., 2006; Ghosh et al., 2016; Liao et al., 2019)* | - Although significant, hypoxia and the formation of carboxyhaemoglobin (COHb) are only a part of the situation<br>- CO is a toxin affecting many systems; participants therefore suffered ongoing problems after exposure was discovered and after any treatment |
| 4. Levels of risk of harm from corresponding concentrations of CO exposure<br>*The idea that a certain level of CO exposure results in a corresponding level of COHb, which in turn results in particular symptoms for that person is erroneous, and was encountered by participants* | - For example, Sarah was told that as nausea and vomiting were symptoms of CO exposure, and as she did not experience them, she could not have had been exposed to CO<br>- Symptoms are varied and it is known that differences in individuals can contribute to differences in symptoms/ Clinical presentation does not correlate with COHb levels; nor does improvement in symptoms correlate with corresponding COHb levels (Hampson et al. 2012; Higgins, 2005) |

In order to provide further clarity, table 14 below records how the discovery of CO exposure was made as well as which participants attended their GP and A&E departments before CO exposure was discovered. Where discovery was relatively swift, due to the high concentration of CO, 'N/A' has been stated. Ajay has been placed into this category, as although he too was unwell on the day before CO exposure was discovered when Tisha was admitted to A&E with suspected syncope and concomitant injuries, his symptoms were not reported and he ascribed his symptoms as being caused by worrying about Tisha. Ajay's condition may have been a useful indication of the true cause of Tisha's symptoms if some further consideration had been taken by the healthcare professionals in attendance (PHE, 2016). Tisha herself recognised there were differences in this supposed syncope from others she had previously suffered, namely, she experienced hearing disturbances and vertigo (Seale et al., 2018). It was disconcerting for her to learn later that she had actually had a seizure, and that the concentrations of CO to which she and Ajay were exposed were potentially fatal (Risavi et al., 2013; Whitson, 2011).

## Table 14: Recognition of CO exposure

| Participant | Group | Visit(s) to primary healthcare provider? | Who discovered the exposure? |
|---|---|---|---|
| **Curstaidh** | 2 | Yes (Curstaidh and son) | Potential for CO exposure realised during work meeting |
| **Bookie** | 1 | N/A | Paramedics/A&E staff |
| **Kate** | 2 | Yes (all family) | Engineer – routine visit |
| **Be** | 2 | Yes (all family) | Engineer – her suspicion |
| **Vivienne** | 1 | N/A | A&E staff |
| **Lizzie** | 2 | Yes (all family) | Engineer – second annual service |
| **Sarah** | 2 | Yes | Engineer – investigating another problem |
| **Ajay** | 1 | N/A | Paramedic |
| **Tisha** | 1 | Admitted A&E day before | Paramedic |
| **Matt** | 1 | Yes (after CO exposure) | Never had formal acknowledgment |
| **Showgirl** | 2 | Yes | Never had formal acknowledgment |

Chavouzis and Pneumatikos (2014) state that there is *"no single symptom or combination of symptoms that may confirm or exclude the diagnosis"* (p.23). In one example, Brar et al. (2014) conducted a review of people who experienced high concentrations of CO and yet only reported feelings of dizziness and suffocation before losing consciousness. Bookie experienced dizziness, while Matt, Kate, Tisha and Ajay experienced intermittent dizziness as one of many symptoms. Pepe et al. (2015) highlight a lack of diagnostic criteria and the complexity of diagnosis, and then present the *"notoriously aspecific"* symptoms in what could be a worsening, progressive list: *"headache, asthenia, nausea, vomiting, transient loss of consciousness, altered mental status, coma"* (p.2; 'asthenia' refers to weakness or lack of energy). It can therefore be seen that despite assertions of a variable presentation, there is almost an 'expected' sequence of worsening symptoms recorded in some of the literature, as discussed in chapter two. From the perspective of many participants, the lack of appropriate environmental history-taking, the idea of obligate, progressive symptoms, concomitant carboxyhaemoglobin results, and absence of sequelae, remain pervasive ideas in their experiences with healthcare professionals.

Bennetto et al., (2008) state that CO exposure is straightforward to diagnose when the right environmental history is present, but complex otherwise; Abdulaziz et al., (2012) contend that CO poisoning remains *"one of the most difficult medical emergencies to diagnose"* (p.421), stating that the non-specific symptoms and variable presentation of exposure are confounding. Chavouzis and Pneumatikos (2014) discuss the diagnosis of CO exposure or poisoning as being based on a triad that correlates with medical model thinking (Gilje et al., 2008): a recent history compatible with CO exposure, symptoms consistent with CO exposure, and elevated carboxyhaemoglobin levels as a confirmatory biomarker. This should render matters more straightforward for any healthcare professionals who know enough about CO to suspect it as the cause of symptoms, yet also highlights how difficulties in diagnosis can transpire, especially when an environmental history is not considered. Symptoms consistent with CO exposure mirror other symptoms of other conditions and not enough is understood about the presence or absence of carboxyhaemoglobin (Bleecker, 2015).

Problems with diagnosis lead to a *"staggering toll of harm"* (Graber, 2013, p.21ii). Kostopoulou et al. (2008), in their systematic review of diagnostic difficulty and errors in primary care, explicitly cite atypical and non-specific presentations as a cause of healthcare professionals missing the correct diagnosis. They also considered rare conditions as a cause. It is unknown how common CO exposure actually is (Wright, 2002; Mandal et al., 2011), but for many, including the participants, symptoms do not follow a recognised progression, but mirror other conditions (Kao and Nanagas, 2006). Lizzie's children suffered from common, viral-type symptoms (Thomsen et al., 2016; Ernst and Zibrak, 1998). Kate had severe, recurrent chest pain (Tirosh and Schnell, 2016). Sarah reported fatigue and cognitive problems (Hopkins et al., 2016), Curstaidh had a chest infection and her son was treated for migraine (Kanburoglu et al., 2016), while Be had mental health problems (de Juniac et al., 2012). Atypical presentations are noteworthy in this context; as discussed above, participants had atypical (akin to Pepe et al.'s (2011, p. 2) *"aspecific"* CO symptoms) presentations, as they did not present with the most typical features of CO exposure in the most typical order. As Kate stated, *"there was always an excuse, always a reason"* (line 1013) providing a rationale for her symptoms, a line of thinking healthcare professionals seem to have naturally followed.

'Everyone seems to be in the dark' was a superordinate theme for group two, but issues around lack of knowledge apply to all participants in some form or other, especially in terms of recognising CO exposure and aftermath. For Tisha and Ajay, a paramedic suspected CO exposure, despite the same opportunity having been missed on the previous day. The dyad were exposed to high concentrations intermittently from a Friday evening to a Monday morning. CO exposure was not recognised, again emphasising the differences experienced by these participants and any accepted norms of CO knowledge. Conversely, Matt's own knowledge of his history were not recognised as being relevant.

If healthcare professionals do not have sufficient knowledge, then they have no power to recognise or even consider CO exposure as a cause of illness, as in the case of Sarah being told by a well-known CO medical 'expert' that her symptoms did not 'fit' and therefore CO could not be causing her problems. It is doubtful that carboxyhaemoglobin testing would be considered in situations such as these. For Vivienne, swifter recognition of the likelihood of CO exposure at the scene may have meant that his needless arrest for the murder of his partner could have been avoided. Be was told that her smoking was the cause of her elevated carboxyhaemoglobin (Chavouzis and Pneumatikos, 2014; Wright, 2002) and that despite a history of smoking without experiencing any symptoms (Arngrim et al., 2014), those symptoms could not, therefore, be connected to her carboxyhaemoglobin levels.

The true incidence and implication of misdiagnosis may not be fully understood (Graber, 2013) as different measurements are used by different researchers and institutes to classify missed, delayed or wrong diagnoses. It is also difficult to measure or ascertain the effect that missed or delayed diagnosis had for these participants. For some participants, such as Be and Lizzie, recognition was further complicated by the presence of an existing, incorrect diagnosis. Sarah and Showgirl had correctly diagnosed pre-existing conditions, as do more than 15 million people in the UK (Department of Health, 2012); again, this also led to some complications in this context, as new symptoms were thought to be a result of the existing conditions.

While the implications of misdiagnosis for the layperson are severe, costs to the NHS are also concerning; according to a Freedom of Information request to the NHS Litigation Authority (Graysons, n.d.), there were 1,280 successful failure/delay and wrong diagnosis claims across all specialties leading to compensation awarded in the region of £197 million for the year 2014/5. There was also an average of 544 written total complaints about the NHS per day for 2015/6 (Bedford, 2016), although information about misdiagnosis was not separated in that data.

## **Taking an environmental history**

Matt’s collapse was attributed to syncope, when instead had the attending paramedic listened to him, it should have been realised that he had been exposed to a high concentration of CO. This would be commensurate with having a working generator inside a property, as Matt did (Buchelli Ramirez et al. 2014). Nicotera et al. (2006) and Zierold and Sears (2015) also found a lack of training and knowledge about layperson environment, and discovered that most healthcare professionals did not ask, or know to ask, about proximity to any known or potential environmental hazards during consultations. This again reflects the experience of the participants here, where they repeatedly sought medical support (mainly group two) or their CO exposure was discovered after they were already seriously ill and in need of hospital care (mainly group one). While the healthcare professionals in Zierold and Sears' (2015) study were more likely to ask about an environmental background if the layperson had an existing history of respiratory conditions including asthma, this was not the case for Showgirl or Curstaidh. Curstaidh was misdiagnosed with asthma during her exposure and later had to contend with marked reluctance from her GP to cite CO exposure as a cause for her symptoms, even though the presence of CO had been discovered and in her case, her symptoms had subsequently abated. It can be determined that without consideration of an environmental cause and knowledge of CO exposure in particular, diagnosis would have remained difficult in nearly all cases, as healthcare professionals do not know to test for carboxyhaemoglobin, which, in any case, cannot be relied upon. A careful environmental history-taking as well as a physical examination at a healthcare professional consultation may have helped establish the cause of some participants' symptoms, especially in group two. Stotland et al. (2014) and Trasande et al. (2010) state that many healthcare professionals lack training in and knowledge of environmental disease-causing agents such as CO. This is despite authors such as Marshall et al. (2002) maintaining that an environmental history should form a standard element of history-taking. Sykes and Walker (2016) caution against the precedence of laboratory testing over history-taking when CO is suspected; this was not a feature of the experience for most participants.

It has long been noted that reliance on testing with technology rather than physically examining laypersons could be potentially problematic: *"it takes a man, not a machine, to understand a man"* (sic) (Allen, 1946, cited in Feddock, 2007, p.374). This perspective is parallel to the medical model notion that the body can be seen as a machine. All its parts work together and, when broken, can be fixed or replaced, part-by-part (Clarke and Everest, 2006). Puri and Shankar Raman (2017) also have criticisms of the modern clinician's reliance on technology and imaging at the expense of the physical examination of the *"real patient"* (p.110) and query whether *"modern day gadgetry"* (ibid) has rendered physical examination irrelevant. Feddock (2007) raised the same question, and taking an historical perspective, demonstrated that technology does not necessarily improve care or rates of diagnoses where inconsistencies between laboratory findings and appropriate clinical skills result in the supremacy of those laboratory findings; healthcare professionals now lack the ability to decipher the whole clinical picture.

## Sequelae

Recognition of sequelae is also an issue. For example, Matt self-reported that he had been exposed to CO, which would have been at a high concentration due to the manner of his exposure, but he was not believed at the time of his exposure event nor when he was reporting sequelae to his GP. It remains, of course, unknown as to whether that GP realised that Matt could indeed be suffering from post-CO exposure sequelae or not. Similarly, Bookie felt that he was behaving in ways that were out of character in the aftermath of his exposure but thought that this was due to the stress of that aftermath. He did not realise that such affective issues and disordered moods could be later effects of CO exposure (Tsai et al., 2014), despite being under the care of GPs, psychiatrists and psychotherapists; presumably, this could again reflect a wider lack of understanding about CO exposure from those healthcare professionals. If healthcare professionals consider the possibility of CO as a cause of their laypersons' symptoms, but have little else than hypoxia- and symptom-centric reporting to help them understand the complexities of CO exposure, despite Roderique et al.'s (2015) assertion to the contrary, then the condition will continue to be unrecognised, misdiagnosed and misunderstood in the future.

Bookie's mother was an older adult, and thus thought to be more vulnerable to the effects of CO (Harper and Croft-Baker, 2004; Su et al., 2014). Bookie himself, however, was middle-aged when the exposure took place; Chavouzis and Pneumatikos (2014) consider being older than 36 as a risk factor for long-term cognitive impairments and recommend that follow-up appointments after hospitalisation for CO exposure should occur to screen for cognitive impairments, but no such follow-up appointments were reported by Bookie. Finally, Tisha and Ajay had largely similar exposures, with differences and similarities in symptoms. Tisha has sequelae, while Ajay does not appear to have them.

## Laboratory testing and biomarkers of 'evidence'

I now consider the relevance of laboratory testing here, and its role in confirming, for healthcare professionals, the presence or absence of a health condition. As discussed in the findings, Lizzie received treatment for an unconnected condition and was surprised at how straightforward her diagnosis and treatment was. She could, however, for this condition describe a set of specific and precise symptoms for which a specific (identifies only the people who have that condition) and sensitive (positively identifies only that condition) test exists (Maxim et al., 2014). Once the diagnosis was confirmed, Lizzie could receive a straightforward treatment that cured the condition and thus alleviated her symptoms. This test is contrasted with using carboxyhaemoglobin as a biomarker for CO exposure, where the test is only immediately sensitive (Bleecker, 2015). A negative or lower reading does not, therefore, mean that the individual is not exposed to CO, yet for some participants the lack of a high enough level of carboxyhaemoglobin, even when recorded days after exposure had been discovered, was taken as evidence.

According to medical model thinking, the presence of a disease is detected by specified diagnostic criteria (Bradby 2014; Gilje et al., 2008). The results of any laboratory tests – such as those that identify measurable biomarkers – (Strimbu and Tavel, 2011) show, objectively, that the disease is present, but often the same clinical presentation of that disease may manifest in more or less severe ways for each affected individual (Sartorius, 2006). This is known to be the case in CO exposure (Higgins, 2005), and presents further difficulties in situations where symptoms are non-specific and objective evidence is elusive or absent. Matt and Showgirl cannot receive a diagnosis that they have suffered CO exposure and now have sequelae as no biomarker can confirm this, despite their own reported evidence of symptoms and sequelae.

Brain scans, such as those featured in earlier discussions about Kate and Tisha, may be perceived to be a sure method of confirming the presence of damage, but are not definitive in the context of CO exposure, either in the literature or for the participants in this study. There may be difficulties in interpretation of scan results; another healthcare professional could construe a ‘normal’ scan as showing irregularities (APPCOG, 2017). Brar et al. (2014) also discussed hypoxic-ischaemic encephalopathy (that is, damage from hypoxia to the cerebral cortex) as an MRI finding in CO exposure which causes cognitive issues; this finding would likely not be revealed in a CT scan (Howard et al., 2012) and may also be present and yet not visible in standard MRI scans (Chen et al., 2012). Chen et al. (ibid) also indicate that the timing of brain scans is important, with certain types of damage to certain structures occurring at different times following discovery of exposure. It is possible, however, that a different method of scanning, such as a functional MRI or a Positron Emission Tomography (PET) scan with contrast (Rissanen et al., 2010) would reveal some signs of damage through CO exposure for Kate, or in others who report such cognitive symptoms. The situation becomes, therefore, that participants may have damage that is not visible on a scan, they may not have had scans, or the scans themselves may not show damage. This can be paired with reliance on carboxyhaemoglobin as a biomarker for CO exposure, and the presence of that biomarker confirming or refuting CO exposure; neither investigation is specific nor sensitive enough (Maxim et al. 2014), participants’ symptoms persist despite lack of test findings, and healthcare professionals often continue to rely on results for confirmation of the presence of disease.

Laboratory testing in various forms has increased exponentially and changed the experience of accessing health care for many people over several decades (Verghese 2008). Several authors have commented on the dearth of healthcare professionals taking a history and performing a physical examination in favour of technological testing; Danielson (2010), for example, stresses the difficulty of balancing the time and resource pressures felt by healthcare professionals against the needs of laypersons, stating that conditions can be missed if technology is overused. It has been reported that laboratory results, including visual testing such as radiology (which includes scan results) are incorrect in at least 2-4% of cases (Graber, 2013) or 7% for ultrasound and CT scanning (Feddock, 2007), with Singh et al. (2009) detailing miscommunication of abnormal test results even in advanced electronic medical systems as a significant issue. Kate's blood tests were *"messed up"* (line 724) by her medical centre, meaning the family have no record of the carboxyhaemoglobin levels that were taken. While she feels that this had little effect on the subsequent court case, as the evidence of the engineer was compelling and the company admitted their negligence, it is difficult to establish the effect on Kate's view of the competence and her trust of healthcare professionals (May et al. 2004). This issue may be relevant as she knows, in hindsight, that she and her family had ongoing CO exposure symptoms which could have been identified by a more knowledgeable healthcare professional.

Be's carboxyhaemoglobin results have already been discussed with regards to smoking; Sarah's experience of her carboxyhaemoglobin result was of being told that the level was too low to cause her symptoms, despite having to wait days for testing. Carboxyhaemoglobin remains the commonest biomarker for CO exposure, despite its reliability not being robustly established (Veronesi et al., 2017; Bleecker, 2015), as is the case with many commonly used biomarkers (Strimbu and Tavel, 2011). As shown, for these participants, it did not always prove to be a useful measure; it only seems to have been a significant factor in Tisha and Ajay's situation, as their carboxyhaemoglobin results, assessed in the ambulance, meant that they were treated with hyperbaric oxygen therapy. As discussed by Feddock (2007), it seems as though the use of technology here, in scans and blood tests, has become a *"gold standard"* (p.375) instead of a complementary method for assessing someone's health status, especially when healthcare professionals lack knowledge. As discussed, diagnosis of CO exposure is problematic (Buschelli Ramirez, 2014; Mandal et al., 2011). CO exposure remains enigmatic, due to the nature of its vague, non-specific symptoms and the wide-ranging lack of knowledge about its dangers.

## Hyperbaric oxygen therapy – available yet contentious treatment

Finally, some consideration needs to be given to the available therapies used for CO exposure. Vivienne, Ajay and Tisha were treated with hyperbaric oxygen therapy, while Bookie and Be had normobaric oxygen therapy. As stated in chapter two, the evidence for hyperbaric oxygen therapy remains contested (Juurlink et al., 2005; Buckley et al., 2011; NHS, 2019), but oxygen therapy is known to remove carboxyhaemoglobin from a person's blood at a faster rate than merely breathing unmodified or ambient air (de Juniac, 2012, Chavouzis and Pneumatikos, 2104). Vivienne feels as though there was an element of chance in his treatment, as he happened to be geographically close to a hyperbaric oxygen chamber and doesn't think he would have had this treatment otherwise. He appreciates that not all healthcare professionals advocate the use of hyperbaric oxygen therapy, but the doctor administering the hyperbaric oxygen therapy *"believed"* (line 2221) that people who had been exposed to CO benefitted from it. Vivienne does not report any sequelae that can be reasonably attributed to CO exposure, nor does Ajay. Tisha, however, is living with some burdensome sequelae. It is therefore difficult to say whether hyperbaric oxygen therapy helped participants' recovery and avoidance of sequelae or not, although, of course, this study cannot lead to any such generalisation. Hyperbaric oxygen therapy remains a contentious but important part of the CO conversation.

## Other treatments

The participants in group two discussed other treatments for the sequelae caused by CO exposure. In part, they were prompted to seek other forms of treatment for their symptoms as they were dissatisfied and frustrated with their interactions with healthcare professionals, where their concerns were overlooked and their voices remained unheard. Parallels can be drawn with the medical model here, and its limitations in treating people with non-specific or ambiguous symptoms (Johnson and Johnson, 2006); Kate, for instance, has become frustrated at healthcare professionals' unwillingness to firmly attribute her symptoms and sequelae to CO exposure and because she wants more investigations to see if her cognition, as she suspects, is declining further. This request has been denied on the basis that no treatment exists. This suggests that any results would lack meaning for those healthcare professionals, although for Kate they would represent valuable further knowledge about her condition and possibly her future.

Some participants have therefore sought their own remedies, as active users of healthcare rather than passive recipients; they had the means to do this through internet searches. Access to the internet has precipitously increased; the technological advances that were once the domain of doctors (Illich, 1976) are now widely available (Nettleton, 2013). These treatments include Sarah's hyperbaric oxygen therapy. This is available to her through a charitable organisation, as self-prescribed hyperbaric oxygen therapy has long been used as a therapy for Multiple Sclerosis (MS) (Boschetty and Cernoch, 1970), although the facilities and thus the treatment at a Hyperbaric chamber differ.

According to existing knowledge, Sarah's carboxyhaemoglobin level is above the usual limit for a non-smoker, which she is, but within the range for a smoker, who would not feel unwell in the way those exposed to CO do (Chavouzis and Pneumatikos, 2014; Arngrim et al., 2014). Her GP has told her that this cannot be the cause of her feeling unwell, as her carboxyhaemoglobin levels are not high enough, yet she is still ill. This reflects Sartorious' (2006) ideas of people who feel ill, despite not having the appropriate indicators for illness, and is not a satisfactory answer for her. Evidence about the viability of hyperbaric oxygen therapy as a treatment for neurological conditions remains contested (Eggleton, 2016) despite some publicised benefits (MS National Therapy Centres, n.d.; Perrins and James, 2005). While we did not discuss the evidence base around CO and hyperbaric oxygen therapy, there does not seem to be any literature regarding its use where exposure is historical. There is also no known biomarker (such as carboxyhaemoglobin) for historical exposure that could indicate the efficacy of the treatment from an objective viewpoint. However, Sarah would rather not be a dependent and passive recipient of healthcare (Illich, 1976; Nettleton, 2013) and has positive affect from securing her own treatment, and indeed, reports feeling somewhat better for it, suggesting that further research could perhaps provide useful insight into this matter. She is also interested in her carboxyhaemoglobin level, and the effects (if any) of the hyperbaric oxygen therapy on that. Matt, Kate and Be also discussed the use of hyperbaric oxygen therapy.

Be was extremely positive about the effects of her vitamin B12 injections. Vitamin B12 in the form of hydroxocobalamin is described as a *"toxin scavenger"* by B12 deficiency (n.d.); there is evidence in the literature that hydroxocobalamin is an effective remedy for cyanide poisoning (European Medicines Agency (EMA), 2015). While its use for CO exposure clearly requires further investigation, this medication was prescribed for Be on the strength of the evidence from people who have used it, which she presented to her GP. This shows this particular GP's preparedness to work with Be, who again was being proactive about her own healthcare.

There is debate about alternative medicines and any treatment without a clear, scientific evidence base, which is related to the discussions regarding the scientific aspects of the medical model. Moore et al. (1985) stated that a main reason for people seeking alternative therapies was that they felt conventional medicine had not worked. These authors were keen to point out that their respondents were not *"cranks"* (p.28) who were lacking in any conviction about the effectiveness of conventional medicine, but that they were just looking for solutions to health problems. This is congruent with the participants here. Relationships with healthcare professionals also feature in this point, as Ernst and Fugh-Berman (2002) concur with Moore et al. (1985) when stating better relationships exist with healthcare professionals from whom alternative medicine is accessed, perhaps because those individuals feel that they are heard in that context. Again, Ernst and Fugh-Berman (2002) also consider that complementary medicine is helpful for more options regarding diagnosis and therapeutic options not available through conventional healthcare.

This aspect of the participants' experience is closely related to the previous discussions about power, in several respects. Participants used the technological knowledge available previously only readily available to healthcare professionals to discover what they could use to help; medical technology is now available to all, not just the healthcare professionals. To participants for whom relationships with healthcare professionals have become conflicted, such actions are empowering. It also involves networking and reaching out to others, and therefore relates to the discussions about connectedness.

## **Summary**

This chapter has explored the participants' findings in relation to the literature on CO and on coping with traumatic experience. I have examined various issues such as power, health and identity, the relevance of which subjects became apparent through the findings. The following, final chapter will conclude the thesis, explore the limitations of the study as well as its impacts, and suggest areas for further research.

# Chapter nine: Conclusion and recommendations

This research has examined the lived experiences of 11 people who were exposed to CO. To summarise, these participants were visited twice using BNIM as a method of data generation. This method allowed for a largely unstructured approach which led to rich, in-depth data regarding what the participants felt was important to them about their experience of exposure to CO. The participants' findings were explored by assigning them into two groups, where group one were exposed to a higher level of CO over a shorter duration, and group two were exposed to lower concentrations of CO over a longer period. I used IPA to analyse the transcripts of those interviews, as an appropriate method of exploring how the participants made sense of these experiences. The four superordinate themes have presented the disruption to the daily lives of the participants, in terms of both the CO exposure and the effects of interactions with others, within the context of the general lack of knowledge about CO. Issues around a lack of knowledge apply to all participants, in some form, as my analysis also shows that many of the main issues are around recognition of CO exposure. It would seem that CO exposure at higher concentrations is comparatively straightforward to identify through presentation, history and presence of carboxyhaemoglobin, providing that an environmental cause for the symptoms is considered by healthcare professionals. This is in contrast to those who were exposed to lower concentrations of CO over months or years. This latter group suffered non-specific yet debilitating symptoms without knowing what was wrong. Some endured what turned out to be needless medical investigations and misdiagnoses, and some were dismissed. Their frustration over a lack of resolution and feeling that they were not heard is heartfelt and evident.

In subject areas where knowledge is lacking, phenomenological approaches such as IPA are particularly useful, as they allow those who have previously remained unheard to communicate their experiences to others. Participants revealed that, whatever form their exposure took, healthcare professionals often did not have adequate knowledge with which to support them, whether that was in the context of diagnosis or provision of care following exposure, or indeed in both situations, as knowledge about CO for these participants was symptom-centric and over-reliant on features such as biomarkers. In addition, the voice of those who suffer CO exposure does not exist in the literature. Many participants in group two felt that as people with non-specific symptoms, sometimes with no proof of cause, that they were dismissed by healthcare professionals, who often thought they had mental health conditions (Johnson and Johnson, 2006). Even when the discovery of CO was made and confirmed by engineers, as in Kate's situation, it was difficult for healthcare professionals to accept the exposure as the cause of symptoms. The severity of the effects of the aftermath of exposure to CO is also a consideration in this argument; for example, the missing flue in her loft meant that Sarah was undoubtedly exposed to CO. This situation was not then given due consideration by both healthcare professionals and the HSE, and therefore the response of these agencies did not reflect the suffering that was caused to her by that exposure.

It should be considered, therefore, that any sort of priority list of symptoms would be largely unhelpful for this group of participants, with or without recourse to contemporaneous CO or carboxyhaemoglobin levels. This is consistent with Wolf et al., (2017) and Abdulaziz et al., (2012), and as with the guidance on other disorders (NICE, 2107), biomarker or scan results that are within normal parameters should not mean that the individual is not living with onerous symptoms or sequelae.

In this study, power is a key issue, due to the feelings of powerlessness experienced by some participants. This powerlessness is centred in their lack of voice, and lack of any voice being heard, and meant that some participants felt vulnerable to judgement and stigma. Again, this highlights that illness experience, including exposure to CO and the aftermath of that experience, is far from being a solely medical experience.

The healthcare professionals encountered by participants in this study include A&E department staff, GPs, nurses, neurologists, intensive care staff, psychiatrists, psychotherapists, cardiac specialists, NHS consultants and rehabilitative care practitioners, and others, but none displayed a detailed knowledge of the effects of CO exposure. Other professional people that the participants encountered include Social Workers and engineers. Again, their knowledge was at times insufficient to provide support to the participants. Overall, I consider that not enough is known about how dangerous CO can be, and how easy it is to become exposed to it. More, therefore, should be known about CO exposure and the variable nature of its symptoms and sequelae; to use Ajay's analogy, knowledge of the effects of CO should become as familiar as the knowledge that drink driving is dangerous. The current work of APPCOG and Policy Connect (Policy Connect, 2019) should continue to expand, so that all professions work together to ensure CO research and knowledge-sharing and can ultimately better educate the public and provide support to those affected by CO exposure. Without such support and collaboration, knowledge levels about CO will remain low and others, such as the participants in this study, will continue to suffer the effects of CO.

The whole experience of CO exposure for these participants is a fragmented process, essentially involving a series of separate exercises and steps by largely autonomous healthcare practitioners and those belonging to other professions. This is in contraindication of Mandal et al.'s (2011) recommendations of a *"rapid co-ordinated multi-agency response"* (p. 149) to CO exposure incidents. Each healthcare professional as reported in this study acts upon *a priori* knowledge (which may well be based on incorrect assumptions), received information, and function largely independently from each other. The healthcare system, for example, is meant to treat illness and enhance wellbeing but operates in a disparate fashion, within the healthcare system itself and with other systems, such as Social Services. Unless the prospect of CO exposure is specifically raised by an expert, there is little prospect it would be considered as a possibility in many of the participants' situations. Such fragmentation further results in the isolated and anecdotal nature of the testimony regarding the cases of suspected CO reported over the years.

The idea that neurological support in the form of clinic-based services for people who have been exposed to CO is necessary has already been postulated (APPCOG, 2017). Returning to Wright's (2002) pyramid idea, most of the research about CO does indeed seem to be focused on the apex, that is, the exposure to high concentrations of CO, and much also seems to be focused on changing the public's behaviour so that knowledge is raised and CO exposure avoided. While both of these aims are important, it is also essential to support those who are already living with the effects of CO exposure, and for whom there has been, to date, little in the way of assistance or understanding from healthcare professionals.

## Impact of this study

Because this research has explored and analysed the specific lived experiences of the participants in the particular context of CO exposure (Baker, 2011), it offers the opportunity to learn about CO exposure from the perspective of those who have experienced it. As stated, the academic and medical literature about CO exposure is from the perspective of healthcare professionals and has concentrated, largely, on the course of the physical symptoms of individuals who have been exposed, without considering the standpoint of those who have endured exposure. The focus in this research has been set to consider their experiences and as such, will benefit others in this position, and examines CO exposure from a wholly different and hitherto neglected perspective.

The accounts of the participants and the resultant systematic analysis through IPA have been used to *"concretize"* this body of previously unexplored knowledge (Hall, 2011 p.4), as well as shed new light on the phenomenon from an alternative theoretical perspective. This will hopefully allow for more consideration to be given to the issues of CO exposure by making these issues relatable and resonant with readers. These readers may be healthcare professionals, laypersons, people with interest in CO due to other professional or personal concerns, or policy makers.

## Limitations of this study

This is a study involving 11 people who gave accounts of their exposure to CO. The accounts provided a wide range of experience in this regard, covering issues around all aspects of what they considered important about the experience, including health, bereavement and support/lack of support from diverse agencies. The study was conducted because no such research with this group has been previously conducted. There was no intention to connect, in any way, any effects on health and wellbeing that occurred subsequently to that exposure with the initial event. Future work could possibly explore the health and wellbeing status of people who have had exposure to CO over time.

Other stakeholders in this area, such as healthcare professionals, were not consulted, although their perspectives could have been valuable. Family members and others who were also affected by exposure were not part of the sample, with the exception of Tisha and Ajay, and Matt. Given that CO exposure concerns families and friends, affecting all aspects of life, this is an area that would benefit from further study.

Some of the participants' biographical information was collected with the accounts, but no focus was given to this as, again, in keeping with IPA the priority was on their lived experience and what they considered to be important about that experience (Smith et al., 2009), especially in light of the absence of any such accounts in the medical and academic literature about CO. As previously mentioned, all happened to be from professional working backgrounds and were living in areas of mainland Britain. The importance of variables such as gender, age, ethnic background and existing health status and so on could be acknowledged in future research. For example, Colahan (2014) devised a novel approach where IPA and Foucauldian Discourse Analysis, which is more concerned with socio-cultural, -economic and –historical contexts, were combined. Perhaps convergence, divergence and any patterns related to these characteristics could be further discerned and analysed in this way, especially in terms of coping with the trauma of exposure to CO, where age and gender appear to be significant. Larger IPA or qualitative studies could also enable any comparisons in the experience of those participants to be collated in relation to any impact such variables may have on the experience of those exposed to CO.

## Future directions for CO exposure and lived experience studies

This study is the first of its kind on the experience of being exposed to CO and living with the aftermath. Issues like CO exposure, where knowledge and evidence of disease is lacking, deserve more careful consideration and research. A clear direction for future study would be to gather longitudinal data from participants. This is a necessity, in order to help identify issues that arise that could be connected with CO exposure, and also, crucially, to continue to enable participants' voices to be heard. This could include, in addition to the participants' focus on various aspects of health and wellbeing, a specific focus on the effects of self and identity, developing that aspect of this study and concentrating on the effects of connectedness and CO exposure.

Perhaps the therapeutic nature of talking about the exposure and aftermath (Richards and Emslie, 2000; Wagstaff et al., 2014) that arose in this study, could be further and more formally utilised in future studies. It is also necessary to gauge how not being listened to or being silenced around the issues raised here affects people's physical and psychological health (Ahrens, 2006). This could help people to make sense of the experience in a more meaningful, knowledgeable and kinder way. Specialist clinic-based services would provide, in addition to benefitting its service-users, an environment in which measurement of any intervention could occur.

Further study on this subject could also include research that allowed for more breadth in the findings, that is, by accounting for factors such as length of exposure, and age when exposure occurred. As IPA sampling strategies and analysis allow the voice of participants to be heard over the claim to representation of the views of a population of all of those who are coping or have coped with exposure to CO (Smith et al. (2009), future research could develop more knowledge on this subject by differentiating between such participants more clearly in terms of matters such as their geographical location and socio-economic status and inherent structures. Further work would be, perhaps, especially telling in a context of increasing inequality and austerity measures. Future directions should also be inclusive of the effect of CO exposure on families, whether those members of the families were themselves exposed to CO or not. CO exposure, as shown here, has long-reaching effects, and consequences can often be felt by the partners, parents, children, and friends of the individual.

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# Appendix 1: Participant Pen Portrait: Curstaidh

Interview: lines 1-641

> *It's really scary to think that you can […] find yourself in a situation like that and I mean I'm [..] educated, er, you know [..] worldly wise, all the rest of it, and I had no idea, absolutely no idea, and I think that was what was so very scary*

How I met Curstaidh: introduced through a mutual contact (networking)

Curstaidh and her teenaged son were living in a rented property which was damp and cold; the *"aged"* boiler was insufficient to provide warmth for them both during the winter months so they had to light the open fire. Curstaidh was used to setting fires, having grown up in a country house, but this particular fire was always problematic and smoke used to pour out from around the fireplace surround. There were also problems with the shower and windows.

Curstaidh is educated and articulate and not afraid to take a stand, but knows that others aren't necessarily in the same position. Despite her abilities and strength of character, she was still in a very difficult position. As a citizen of a developed country with a sophisticated infrastructure and rights afforded to her, she was still powerless and frustrated. She didn't ever receive any acknowledgement of the danger that she and her son were in from the landlord, there were just denials and seemingly no redress; nor did the GPs at her practice show much understanding beyond treating her and her son's immediate symptoms. We met at Curstaidh's work, conducting our meeting in a private room slightly away from her workspace and colleagues, in an office with glass partitions for walls. This may have influenced the meeting. Curstaidh sometimes used management-type phrases such as 'moving forward' and 'going forward'. We perhaps may have had a different flavour to our encounter if we had met away from the work situation and the 'feeling rules' of the organisation. All that aside, I was welcomed very warmly and once again felt that it was very good of her to share her story; I wanted to make the most of the opportunity that she was affording and do justice to her story and her generosity.

Curstaidh talked about the health problems that they suffered. She had recurrent chest infections, for which she underwent several investigations and was eventually given an inhaler and told she had asthma. Her son had severe headaches, which were initially thought to be migraine. He missed a great deal of school during this period, and did not do well in his GCSEs as a result. Curstaidh described days when he would try to eat, and then vomit and be ill for the rest of the day, or would make it into school, only to have to be picked up and taken home again. Both occupants therefore had repeated GP visits, investigations and treatments, but no environmental cause was considered.

She found out that CO could be the issue through a discussion at work; she spoke to a firefighter who gave her a Toxirae. It gave a very high reading in the property straight away. The same firefighter put her in touch with a charitable organisation. She was also put in touch with the HSE and another body, but was not advised at any point to get a carboxyhaemoglobin level checked, which meant that it was very difficult to take the landlord to task for not maintaining the fire and chimney correctly.

Curstaidh felt it was more important to stop the same scenario from happening again than to claim any sort of reparation. The relationship with the landlord was an issue here. Initially seemingly very good, it deteriorated to the point that he handed things over to an agent while Curstaidh was trying to take him to court over the CO. He had seemingly made rough attempts to solve the various issues with the house, but never successfully. Curstaidh was concerned about this because she was worried that as a landlord, he would try to be as negligent with other tenants. Various professional bodies and organisations were approached for advice; Curstaidh had to deal with medical and legal issues that were very frustrating and ultimately fruitless. Eventually, however, it seems that the landlord had fixed the problem, after Curstaidh and her son had moved. They are both extremely vigilant about the possibility of CO in other properties now; she has a sense of dread when she hears of people who have suffered fatalities because of CO. She says that looking back it was a *"hideous"* time, not least because she did not know whether her son (and herself) had suffered irreparable harm from renting a property from someone she initially trusted, but who turned out to be failing in his duty of care.

Curstaidh works in a professional occupation. The exposure occurred around six years before interview, and Curstaidh delivered a fact-based account, without displays of very strong emotion. She talked from a position of altruism; of wanting to help me with my research by sharing what had happened to her. At first she described the events as a blip, an aberration, but then expressed anger and frustration at the actions of her rogue landlord, whom she initially trusted. She also elaborated on the fear that she felt when contemplating what might have happened to her son. It was a very eloquent, articulate and focused account, told in chronological order, even though it seemed to be 'naïve' rather than 'rehearsed'.

# Appendix 2: Pen portrait: Bookie

Interview one: 1-667

Interview two: 669-1423

> *There's no such thing as justice [..] and, he says, you'll never get justice […] so it's all nonsense*

How I met Bookie: through a CO charitable organisation networking event

Bookie was with his mother, who was aged 83 and who lived with him, when cavity wall insulation was installed in the house. This happened four years before our meeting, when he was in his fifties. He feels that the company who installed the insulation had pressured his mum with many cold calls in order to get this work completed on the house. The installation led to disconnection of the boiler pipes (the boiler was fitted to the inside of the adjoining garage wall) that take away the fumes of combustion, leading them to circulate through their home and causing his mum's death. Although he was also suffering with the symptoms of exposure, Bookie managed to call an ambulance and was admitted to hospital for overnight oxygen therapy. He learned that the paramedics who had treated him had themselves been admitted, as they were also suffering the effects of CO exposure. He recalls that he did not sleep all through that night as he thought that he'd never wake up again. Bookie's account is focused on the aftermath of this event, with trying to come to terms with what happened and seek justice for his mum, and cope with the guilt that he naturally feels around her death and his survival. People did wonder why and how he had survived and she had not, although he was categorically told by the coroner that he was in no way to blame. Bookie also faced the gradual realisation that justice was to remain elusive even after years of stressful legal wrangling.

He had lost his brother to a brain haemorrhage and his father to a perforated gastric ulcer, so has had to contend with the sudden and traumatic deaths of close family members. The death of his mum was different for him, though, and to this day he feels that he has not come to terms with her death. He gave many detailed descriptions of the proceedings that followed, where he was interviewed by the police and the press, and where he tried to seek rectificatory justice. He felt that he was ill-prepared for the lengthy court process, where the defence (the company who had done the installation) could only try and destroy his character. The company stated that they had told him not to turn on the heating after they had gone, but Bookie hadn't thought anything of this throwaway remark, which had been further qualified by the worker saying that they 'should' be alright as the boiler was in the garage. This shows the lack of knowledge from the person installing the cavity wall insulation. By

Bookie lives in a rural location. He moved there after the CO exposure. It is about 90 miles from the city where he lived all of his life until the exposure which killed his mother. He is a creative person and enjoys collecting antiques and unusual items of art; this gives his home a very interesting atmosphere. His chosen name is from a business that he had years ago; I wondered whether he considered this time to be one of contentment, and that he picked it because it harked back to a happier time. He also gave the term 'Honest' as another choice of name, perhaps reflecting both his character and the perceived belittling of that character during some of the court proceedings. He doesn't work formally at the time of interviewing, but is very occupied with business that he has an interest in, which is situated in the nearest large town. He gives the impression of being enterprising and shrewd, as well as being a very kind ("don't let your tea go cold, love") and straightforward man. He spent a long time setting the context of his narrative; I wonder too whether he was merely setting the scene, telling me how and why he and his mum came to be living together, and how they came to have the cavity wall insulation installed, or whether perhaps he felt some anxiety about relating the actual contents of what happened. There could, of course, be many reasons.

industry guidelines, the worker should have called an engineer who would have turned off the gas supply immediately and put warning notices on the boiler, but the worker did not know to do this, and so the CO exposure happened.

Bookie's is an account of powerful people, and people who don't understand what it is to be helpless and grieving, or don't seem to understand that those in that position deserve our empathy and support; Bookie's view is that perhaps they don't care, or don't see any part of human suffering to be as important as business and profit. Bookie, despite his not inconsiderable talents as a communicator, was not in a position to change the course of the storm in which he found himself. One barrister said that it was his (Bookie's) 'fault' that his mum died; and his sister and niece, and others, seem to have selfish interests rather than trying to help Bookie gain justice. This is his life world. He didn't talk about any injuries from CO; he didn't appreciate that the mental and emotional health effects that he talked about could be the effects of his exposure. It is, however, very difficult to establish how much of these effects were from CO and how much they were a result of having to cope with grief, shock and stress.

The 'cavalry' in his account are the Health and Safety Executive, because they were already investigating the owner of the company. He also states that one solicitor was very supportive in some ways. The HSE took the firm to Crown Court where they were heavily fined. This was a protracted process, as it was more than three years after the exposure. This was a protracted affair, the stress of which prompted Bookie to ask me to warn other people off going to solicitors. He was very clear about this and mentioned it several times; for Bookie, it just was not worth all of the stress of going through the court cases. He doesn't feel that the monetary sum that he received in any way compensated for what he went through, nor does he feel that the negligent party, the man who set up the cavity wall insulation without ensuring that the operators had sufficient knowledge to protect those for whom they provided the service, was appropriately admonished. This man was fined, but free to go about closing down that business and setting up another, while Bookie was left to cope with probably the worst trauma that a person can go through.

# Appendix 3: Pen portrait: Kate

Interview one: 1-905

Interview two: 907-2520

> *But I didn't realise that, you know, we're in 2016, that I would still have daily, issues from being poisoned [..] you know, so the nominal amount that we got [.] means nothing to me,*

How I met Kate: through a CO charitable organisation

Kate moved into a newly built house with her son, then aged six, and her then husband. A professional person, she ran a very successful business from home. She began noticing that she wasn't well; she would have problems focusing on her work and with her memory, and she would be dizzy. She would really notice this when she came home from holiday, when would suffer with painful headaches, nausea and vomiting. She took her son to the GP several times with abdominal pain. The GP could find nothing wrong and suggested that the child was trying to get out of school. He would sometimes have headaches too, but again, this was another non-specific symptom. Her husband was also unwell, developing an enlarged heart and anxiety/panic attack disorder. Her work partner, sharing the home office, had some episodes of illness too, one of which was so bad that she called an ambulance, but nothing was seemingly connected and certainly no environmental cause was considered. She was not in a position where she suspected or somehow felt or *knew* that something was wrong; she just assigned the symptoms to other causes.

Kate was admitted to hospital with chest pain; the pains were so bad that Kate had collapsed and lost consciousness. She spent a week in a cardiac ward, where the pains were only slightly relieved by GTN spray. She was asked several times if she was a cocaine user, as the healthcare professionals believed that her symptoms were a 'classic' indicator of cocaine use.

Although they had used to argue over it, Kate's husband had always wanted the windows open at night and she now feels that this saved their lives. While the family were on holiday, levels of CO had built up in the closed-up house, so that Kate would feel ill and suffer with headaches, nausea and vomiting on her return. Discovery of low level exposure to CO came about when the warranty on the boiler expired after three years of the family living in the property; the boiler was duly serviced, and it was found that the flue was not connected with a male/female connector, so there was a gap between boiler and flue. There was another gap where the pipe of the flue ended under her bedroom floor, so even though there was what looked like a flue coming out of the wall, that portion was not connected and fumes were just circulating in the house.

She contacted a solicitor and as part of the proceedings was seen by several consultants, including a neurologist and a toxicologist. She has had many investigations for many symptoms that have developed after the source of exposure was discovered and dealt with; she finds difficulty in retaining information, and she has struggled to teach herself to read again, after losing the ability to do so. This coincided with the onset of a severe depression and the loss of her business, as she was not able to perform as she had previously. She has been diagnosed with Fibromyalgia and has episodes of double vision, explained by neurologists as a sort of visual overload. Although her MRI does not show abnormality (she has never had a Functional MRI, however) her Kendrick test suggested that she was performing in the region of someone who was 85, rather than still in her 30s. She has been told that she presents as someone with the onset of vascular dementia, and that there is not much that can be done for her. She was perturbed to hear from specialists that they had not seen anyone with the effects of CO exposure before.

She has had surgery on her hands to release nerves, in an operation similar to that used to treat Carpal Tunnel Syndrome, even though she does not have that; it has helped, but she feels weakness in her hands and has feelings that she can best liken to shin splints in her forearms. She has issues with tingling and numbness too. Her legs and feet are also painful, but the equivalent surgery is more complex and she is not reassured that it will be even as successful as the surgery on her hands. She cannot take medication, as she has become very sensitive to possible side effects which did not happen before. Like her husband, she also started experiencing trouble with spelling and writing, which had also never happened to her before.

As stated, her husband developed anxiety and a panic attack disorder, while her son started to struggle at school. Previously he was known to be a very bright boy; he was one the youngest members of MENSA at the age of six. After exposure, however, he was found to below average across the board. He requires extra tuition and has extra time for exams, and has been diagnosed with dyspraxia.

She tried to return to university to retrain for another career but had to leave the course, as her problems with reading and retaining information meant it was not possible for her to progress. She also went through a long period of being disorganised and unable to keep track of things like presents bought for the children and items bought from the internet, and keeping track of appointments.

Juxtaposition – she speaks of 'the brain' rather than 'my brain'. Her brain/mind is now a separate entity that absorbed most of the damage – it's the damage that is almost causing the separation? So she's looking at her own brain/mind as something that is lacking now, and stops her from doing the things that she used to do and still wants to do. But she is her mind??

I've found it interesting that we never mentioned blame, really. Although she blames the builders for their negligence and says it never should have happened, as far as the HCPs go she is more forgiving of the fact that no one knows what is up with her and no one can support her through this. She does blame the system – deficiencies on societal/structural level, not individual approach fault

Emotional effects hard to disentangle. The emotional effects of the trauma of finding out that you're exposed and that's why you've all got problems, that's massive. And some of the issues around the shock of this traumatic event and the brush with death, because that's what people think of about CO, are similar; but we also need to consider the possibility of the psychological effects of CO itself

Kate wants to know what others have to go through, if there is any way they can all supported, she doesn't want to be alone so much, she wants some common human understanding about her condition and her experience. She has quite a deterministic attitude, in that she thinks things happen for a reason, so I don't know, maybe she thinks there's a higher power somewhere that is directing the traffic down here, and as part of a bigger picture that we can't see she's able to believe and take comfort that all that happened to her because that's what needed to happen, for some reason. She sees that she had a choice to be weak or strong in her reaction to what happened, and, commendably, she chose strength.

Her husband thought that she was less tolerant and shorter-tempered, that her personality had changed. She also suffers from migraine now, again, it difficult to say that the CO exposure precipitated that or the fibromyalgia, but she certainly had neither condition before exposure. She still lives in the house where it happened, but wishes that she could move – it doesn't feel like home to her anymore.

She has had a good deal of press involvement and has become an integral part of a CO charity. She's so energetic and determined to raise awareness. She hates the term victim, she's against the *"woe is me"* mentality that she feels would label her as incompetent. She actually feels lucky not to have died or lost anyone. She feels that the research *"has been needed, for a long long time"* and was really happy to be a participant.

# Appendix 4: Pen portrait: Be the change you want to see in the world (Be)

Interview one 1 – 1864

Interview two 1866 – 4607

> *I was a good mum before that [..] I really really was, and my children they, they achieved well and they were happy, and they were rounded everybody said they were, and they were kind children [..] and they stole all of that from us (cries) and they stole their mother from them [..] that's how I feel*

How I met Be: through a CO charitable organisation

Of course, Be was, and remains, a 'good mum'. She talks proudly about her children, and with great love, but also with anxiety about their past and present symptoms and about what the future may hold due to their CO exposure. The quote above refers to the period that comes toward the end of six years of lower level exposure, mainly due to issues with the boiler in their home. Be was diagnosed with depression before the CO was discovered; even though all of the family displayed various symptoms, no-one suspected an environmental cause and the CO remained undetected for a long time. Once it was found, Be then was not taken seriously in her concerns; despite being an educated, professional, articulate person, and despite trying desperately to raise the alarm, the problems were attributed to her mental ill health.

Before the exposure, Be and her husband and three children had enjoyed a *"lovely"*, fulfilling life. Both parents worked, the children were involved with sports clubs and social events, and Be enjoyed having many social events at their home. Be was keen to give a full context to show that they had a good, and entirely normal life, with joy and sadness and busy times that they all coped with. They moved house in April 2007, when all three children were primary school age, and the child of some very close friends died from a childhood cancer around a year later. Be told about me this as it was very painful for the whole family; it did have a significant effect on her children, the youngest of whom in particular was this child's best friend.

Be reports feeling depressed around this time, but assigns this to the events surrounding the family. She also took her youngest daughter to the GP with numbness in her extremities, but says that all of the children were unwell. The youngest and the middle child suffered what was deemed to be a viral infection where they were very ill. The youngest in particular was affected, needing to stay in hospital for a week and then needing to use a wheelchair when she was discharged, as she was very weak and had reduced feeling in her legs. She was also showing signs of hyperacusis. When she was home, Be reported that her behaviour underwent a dramatic change. She started to show signs of aggression, marked mood swings, and school refusal. A change of school helped; but she would complain about the collar of the shirt and the back of her school shoes being really painful. She would go and stay with Be's parents and recover, and then the episodes would start again when she returned home. At some point before the change of school, she was taken to A&E and given a thorough examination; she was almost transferred to GOSH but doctors disagreed about whether she should be; the senior doctor in that discussion thought not. Be did not know the rationale behind either of the doctors' decisions. The middle child was generally unwell too, and the eldest daughter suffered from nausea and vomiting. Aches and pains, rashes and flu-like symptoms were common among all three children, for the duration of this period. Even now, they are tired all of the time, and suffer headaches, coughs, and flu-like symptoms. Be’s cognitive issues persist, although they are lessened. As time went on, the husband had some syncopal episodes, and all of the family developed issues with diverse symptoms such as back ache, concentration problems and trouble with organising and planning. Be’s depression was becoming worse, and she gave up work, thinking that her new job, working from home, would be more manageable; she had to give this up too, though, as she couldn’t keep track of spreadsheets and telephone calls as her memory and concentration problems worsened. It was around four years after the house move, by this stage. She had started taking antidepressants, but felt worse on them, to the point where she wasn’t attending to her personal hygiene and would only bathe if someone pointed out that she smelled; she was pointing out the same to the children. She tells of shouting and screaming all of the time; she describes this as a time of *“absolute chaos”.*

She had had ideas that their troubles were something to do with their environment, but she said that she couldn’t put the pieces together. One day, however, out of desperation, she phoned the gas emergency helpline number on the meter cupboard door. The engineer declared the boiler to be at risk due to the position of the flue and the incorrect seals. She was told to contact the maintenance provider (who would have refused to attend had the first engineer not reminded them that they were obliged to). The second engineer came five hours later, rather than the promised ‘within the hour’; the windows and doors had been open for all of that time, as per instructions, and yet his alarm sounded as he walked over some bowed floorboards. Engineers have told her since that there may have been a collection of CO there. He immediately said the alarm was faulty, which did not sound convincing to Be. Her husband was home by then, and the second engineer told him that the boiler was safe, but that they should make changes in due course, which he accepted; he did not seem concerned.

**Notes from reflective journal entries**

Quite often, she brings in someone else, e.g. she’ll be telling me about some encounter/conversation/occurrence, and she’ll say that someone else was there who can verify that, as if I won’t believe her? Is this an effect of not being believed for so long?

The thing is, nobody was doing anything, nobody listened, nobody believed that there was a problem other than Be’s mental health, even [name of husband]. She was driven into panic and desperation by the fact that no-one would listen. It’s weird, though, they didn’t believe the girls either – this is the most troubling in terms of sexism and not believing children. Or, they maybe believed some of what they were saying but did not have the knowledge to connect it in any way to CO. No-one lives in a universe where CO is believed to cause continued and non-specific and very wide-ranging symptoms as a result of CO exposure; this belief endures through a short recovery period – you can’t have symptoms after you’re removed from the source, as it’s left your blood. Be’s 60 days is a weird one – I think it refers to the 60-90 day life cycle of RBCs, but obviously I can’t be sure??

Be was accused of having a MSBP – labelling her as someone who would harm her children is obviously devastating – huge stigma. She is thought to lie and exaggerate, she is viewed with suspicion and is not believed. If this was ‘just’ mental illness, how would that attitude help?

Some people with MSBP, or ‘disease forgery’ seek the hero or victim role, rather than the sick role. Wow. They are described as ‘perpetrators’ who can be deceiving and manipulative – massively pointing to abuse (choice) rather than a medical condition (random occurrence). If you are a protective parent, when does that become an over-protective parent? Being over protective *and* negligent are *both* part of MSBP. If you don’t have MSBP then you are ‘innocent’?

Fear is the hallmark of this time of her experience; it was set to continue for a long time. Be was so frightened that she removed the children to a local hotel, and called an ambulance the next morning when the eldest child was poorly. They took the family home; the GP wasn’t interested, and neither was the Environmental Health Officer that she also phoned. There followed a long period of trying to find someone to believe her, in spite of GP, A&E, and Social Services and mental health services involvement. The healthcare professionals largely disbelieved that there was an environmental issue; Be became terrified that she would be sectioned or that the children would be removed from her, as she was accused of having Munchausen's Syndrome by Proxy; in other words, the children's symptoms were being fabricated, induced, or exaggerated by their mother. Her GP had told her that she would not have any ill effects from CO exposure after 60 days; she does not know on what this was based, and of course, it simply is not the truth.

Be started to develop breathing issues and chest pains, and was frightened that she was going to have a heart attack. She was told that she was too stressed, and that she should calm down. She spent a lot of time outside after that, as she could still get no-one to listen to her concerns. The police were called at one stage, as she refused to allow a psychiatrist to visit her eldest child at home, as this was what the child did not want. She asked the officer to talk to her neighbour, and cites that the amount of time she spent outside allowed her to collect her thoughts enough to have a rational conversation with the officer. She started to experience pain in her head and neck and photophobia which were most severe; she asked her parents to take her back to A&E where she started having and what she describes as *"like electrical pulses"* going through her body, and these were terribly distressing, *"like hell"*. Throughout this time, she remained terrified.

She was treated with some kindness by some healthcare professionals, but with disregard by others. She was found to have elevated carboxyhaemoglobin levels, but this was not considered significant as she was a smoker, despite her symptoms. She was diagnosed by one A&E doctor with chronic exposure to CO, she was given oxygen therapy and she was believed. She was then treated most unsympathetically by doctors who thought she was hyperventilating, and discharged. The psychiatrist she saw, however, discerned that she was not psychotic but that she was under immense stress. The psychiatrist had prescribed medication, but she had read an article by someone who said that taking psychiatric drugs when suffering from CO exposure exacerbated symptoms rather than alleviated them. She stopped taking them and began to feel better, even though she could not tell either her husband or doctors that she had stopped taking them. After the children had been upset by the social services interview, she took out a charge of harassment and informed the GP surgery and the school that she was doing so. She heard that social services had closed the file soon after that, but life continued to be unbearable.

The overwhelming fear did not abate. She became frightened of driving the car, for fear that the wheels would somehow come apart. In hindsight she feels that she may have been having balance issues. She was confused and used to lose her way often. In the car, she could not drive and follow the sat-nav. Her mood was very low, as was the mood of all the children – she was told that she was transferring her mood to the children. At some point, she was misdiagnosed with ME.

This state of affairs continued for another nine months, after which they moved out of the house to let some building work be done by their insurance company. An engineer looked at the boiler, and his monitor alarmed after he had run it for a short time and the boiler was finally condemned. She was seen by a toxicologist, but had to provide readings from the boiler – which seems of little use after the family had been exposed to low levels of CO for six years. She was discharged soon after.

She has found considerable relief through vitamin B12 injections. The constant pain that she feels in her limbs is resolving and her mood has lifted considerably, and her concentration and memory have recovered slightly.

This was one of the longer and more complex sets of interviews as reflected in the length of this pen portrait; Be was very relieved that the research was taking place and that someone was listening and wanted to tell me everything in detail.

# Appendix 5: Pen portrait: Vivienne

Interview one: 1-1237

Interview two: 1239-3519

> *I don't really like the expression that erm it gives, you know someone who has died in a particular accident and you do general things about it, like gathering money or awareness or raising awareness, that that gives that death, meaning [..] no it doesn't, to be perfectly honest, em, I would much rather have [name of partner] back and never have heard of carbon monoxide*

How I met Vivienne: through networking within the CO community

Vivienne's account is perhaps the most 'rehearsed', as he has devoted a great amount of time talking about what happened, to the media and to policy makers in order that others are aware of the dangers of CO. Five years before the interviews, Vivienne and his partner were on holiday and had a bucket-type BBQ for cooking meals. This was their usual holiday habit and he feels that they must have been exposed to CO on plenty of other nights. This night, however, Vivienne's partner died from higher levels of CO exposure, and he survived. He was extremely poorly; not only was he exposed to a high level of CO, he had, at some point in the night, lain on his arm and in his unconscious state did not move off it again, to the point where he suffered a serious compartment syndrome and crush-type injury to it.

Vivienne has persistent daily reminders of his trauma; he cannot possibly escape reflecting constantly on what happened (even if this is not entirely conscious) because he has a huge scar on his arm, the implanted spinal cord stimulator for the neuropathy and he has to take so many painkillers that he has devised a spreadsheet to keep track of them all.

He campaigns a great deal; he thinks of being arrested and how devastating that was, and wants to avoid that happening to others. He has progressed to a level of functioning that is similar to his previous life; but this was hard won. His idea is that his partner was a victim, as she lost her life, but he is a victim because of what he lost too, physically and emotionally. Although he identifies more with the term 'survivor', this speaks of their CO exposure as a life-changing, horrible, shattering experience, and yet he can still share the account, and still laugh, and still work so hard to avoid it happening to others.

Vivienne's story resonates with me; I go on similar holidays and I would not have known that you could be exposed to CO from a cold, used BBQ.

On waking up, on that morning, Vivienne recalls the difficulty in accessing help, as he was extremely ill; too ill to move or really comprehend what was happening. He did, however, realise that his girlfriend had died, and was alone with her while he was shouting for help for a long time. He was able to convey the seriousness of the situation to a 999 operator on his mobile phone, but he was confused and could not remember where he was, and his voice had *"given out"* before anyone finally heard him and came to help. He realised, during this time, that his arm was badly damaged. He had pain in his shoulder but could not move or feel his arm.

He was treated at the site by paramedics, and arrested by police for the murder of his partner before being removed to hospital. The memory of this persists, even though he was dearrested some hours later. He spent four weeks in hospital, two in ITU and two in a general ward. He received hyperbaric oxygen therapy. He also had two elective fasciotomies for the damage to his arm, resulting in a long scar, and then six further elective closures of that long wound. Healthcare professionals later told him that they were not sure that they had done the *"right thing"* for him with this treatment plan. They had come close to amputating his arm as the raised creatinine levels that were a consequence of the injury were affecting his organs; his kidneys, in particular, were close to failure.

There has been good recovery for his arm; he records that most of the mobility and sensation are returned, after intensive and drawn-out physiotherapy and rehabilitation (which he had to push for, and some of which he sought privately). He developed a complex regional pain syndrome, unfortunately, which required implantation of a Spinal Cord Stimulator to treat this painful neuropathy. He stills takes many pain killers every day.

His dealings with the press have largely been very positive, and he devotes great time and effort into raising awareness of what happened so that it can be avoided by others. Initially, though, some members of the press were intrusive and disrespectful.

# Appendix 6: Pen portrait: Lizzie

Interview one: lines 1-377

Interview two: lines 378-1141

> *None of these things were insurmountable […] all it would have been to it and needed was to address the problem, either with B12, or fixing the fire [.] practical things could have been done*

How I met Lizzie: through another participant (snowballing)

Lizzie's exposure to low levels of CO happened over two years in the 1990s, and Lizzie and her now adult younger child and grandchild still live in the same house where the exposure took place. She had moved into the house with her husband, and two children, who were then aged eight and two. Lizzie reports some ongoing disharmony in the relationship with her husband and cites that the move was seen by them as somewhat of a *"fresh start"*. The previous owner had sold the house as her husband had died very suddenly of a *"heart attack"*. It may be that they also had lower level exposure that could have contributed to his sudden demise.

I initially wondered if Lizzie really met the inclusion criteria because of her other condition, the misdiagnosed Functional Neurological Disorder. Her situation reflects the subtlety and confusion around CO, though, where nothing particularly makes sense and CO makes everything worse. Co-morbidities being as common as they are, this is kind of obvious. The situation recalled my initial aim of talking to people with clear and as the literature describes it DNS, when the literature only talks about individual cases and there is nothing about people's perspectives.

It seems that there is never going to be a 'perfect' set of CO symptoms and/or effects. Again, CO is so hard to pin down. There is always another cause of illness and death when it's chronic. Could this be something that is just about chronic/occult exposure? Not that I've had an occult exposure presentation, by definition, as it ceases to be occult once we know. It's occult for all of those with chronic exposure up to a point here, though, and they are telling me retrospectively, about the time when they were ill but didn't realise why.

The exposure came from a gas fire that was used as primary heating for the downstairs living room and was therefore on for most of the time during the colder months of the year. Lizzie's husband was not in the room for most evenings, preferring to spend time occupied with hobbies in another room or out of the family home, but Lizzie and the two children were there constantly. Lizzie already had a health condition, but the two previously healthy children soon began to suffer with stomach upsets (to the point of incontinence), sleep disturbances and irritability; non-specific symptoms that are common enough in young children and could easily indicate a range of myriad conditions, many of which would be self-limiting illness. The younger child also suffered with burst eardrums and sleep disturbances for both of those winter periods. The family dog was older but had been previously very healthy. He deteriorated so quickly when they moved, though, that he had to be euthanized. Lizzie had what she describes as breathing difficulties, pains, tinnitus and syncope, memory, co-ordination and cognitive issues that were substantial over the two years, particularly during those winter months, and some of which have somewhat ameliorated since.

Lizzie had a diagnosis of Functional Neurological Disorder when she moved into the new house. Many years later, the symptoms that prompted this diagnosis would be identified as a vitamin B12 deficiency, but this was unknown to Lizzie and the doctors when living in her new house and experiencing a great deal of burdensome neurological and digestive symptoms. This added to the ‘confusion’ – although the children themselves had been previously healthy, it was impossible to tell what was causing Lizzie’s new decline in health; whether it was her existing condition, or whether it was something else that was causing more and more diverse problems. The nature of Functional Neurological Disorder, as a blanket term suggesting a psychological origin to a physical disorder, greatly added to the difficulties she encountered with talking to her GPs. She feels that this diagnosis meant that she was not taken seriously when reporting her new symptoms and the children’s symptoms to healthcare professionals. She actually reports being laughed at when presenting herself for appointments, including one occasion when she had collapsed in the car park of the GPs’ surgery. It turned out that her husband was talking to her doctors without her knowledge, and stating that she was in some way fabricating symptoms as part of a mental health condition, and it was this that had triggered the Functional Neurological Disorder diagnosis.

The problem was found in the second winter of their residence, when the second annual service of their appliances took place. Although the first engineer had, in the previous year, not indicated that anything was amiss, the second engineer condemned the gas fire and asked if anyone had been unwell in the household. It seems that he correctly surmised that they would have been experiencing symptoms, as the chimney space behind the gas fire was blocked with rubble from a building job that the previous residents had commissioned. The exhaust fumes therefore had no way of being taken away from the room where the unsuspecting family spent their winter evenings. Lizzie did want to redress the fact that the first engineer should have reported on this situation. Unfortunately, the survey that had been undertaken before they moved in had reported clearly on the rubble blocking the chimney.

The husband left the family home and the couple went through a difficult divorce, but Lizzie reports that her health improved and that this was due to the discovery and subsequent removal of the CO. Each stage of analysis brings the researcher closer to the depths of the transcript. I can see, and reflect on, how much Lizzie’s positive attitude is a feature of her story, how distressing those times were for her, and how complicating her husband’s responses to her and the children’s illnesses were. I remember how much she laughed throughout the interviews, as well as how much she cried and swore and remembered her anger and pain. Lizzie presents some complexities in terms of research, as she was living through some difficult and complicated times (her misdiagnosed health condition and her relationship) whilst also being exposed to CO. This is, however, a reflection of our lives. CO exposure happens to people when it happens, so the fact that she was ill from CO exposure whilst already living with a misdiagnosis that meant she was not believed, was in a difficult marriage, had two small children, and was continuing to work at her profession all at the same time means that there is a rich context to her situation, and some of what she endured as a result of exposure had clear established roots from before she ever moved into the house where she was exposed.

# Appendix 7: Pen portrait: Sarah

Interview one: lines 1-1225

Interview two: lines 1226-3503

> *Your life is just slowly falling apart, and the doctor is saying there's nothing wrong with you, you're like [.] I know there is [..] and of course the only logical suggestion is, you're mental, that's what's wrong with you [..]*

How I met Sarah: through her contacting HEIs where she had read about CO research taking place

This is a fresh experience for Sarah, as we met just a few months after the exposure in her home was discovered. Her anger and frustration is apparent throughout. She looked for research about CO that was ongoing, so she wasn't invited to be a part of the research in the usual way. She also talked about the friendship that has grown between her and her neighbour, also affected by CO. She, I think, would have liked the neighbour to talk to me, but this was not what the neighbour wanted to do. This has set me off thinking about the role of 'voice' in this research. I have, I think, been making a somewhat automatic assumption about a lack of voice and lack of empowerment that I 'assume' the participants were objects of, even though they have all been really, really articulate and I know that some of them campaign and are used to talking about what they have been through. They have, however, loads to say about CO exposure and their experiences – they have learned so much about it. It's not that they don't have a voice in that they have nothing or little to say about CO exposure and their experiences, it's that they haven't been heard in this forum (academic research) before – the difference may be subtle to onlookers, but I don't think it is for them or me.

Sarah had moved to a new job, about which she was passionate, in a new city, three years before we met. Initially, she was making new friends, and building a life for herself. She was careful to point out early on in her account that all the gas safety checks and servicing of appliances were carried out annually. This meant that although she realised fairly quickly that she did not feel very well when the heating was on, she did not connect those feelings with anything to do with the appliances themselves, assuming that they were safe.

When she presented with symptoms of extreme fatigue, GPs would do the usual tests (for example thyroid and blood glucose) and then dismiss her when no problem was immediately evident from those tests – they did not know what was wrong, if it was not those usual culprits, and she felt that they were not interested in investigating further. She had a pre-existing condition of PCOS with insulin resistance (meaning that her body cannot efficiently use the insulin that it produces). One of the symptoms of this condition is fatigue. She described this condition as *"mild"* and had been managing it very successfully with diet for many years. She was referred to an endocrinologist for her fatigue; this consultant, unfortunately, was rude and aggressive (*"he actually got shouty"*) and wrote letters to her GPs saying that there was nothing wrong with her, inferring that her symptoms were exaggerated or fabricated, and that she didn't even have the initial condition at all, let alone that she was experiencing an exacerbation of that condition. She was so perturbed by this that she saw her old consultant privately, who did confirm that she still had that same condition; nevertheless, she felt labelled by these actions.

As time went on, her fatigue became so extreme that it severely affected her life. She did not go out with friends, she did not progress in her career as she thought she would, not applying for promotions, etc.; she was cold all of the time, she would forget to do things like brush her teeth or apply deodorant unless she stuck strictly to her routine; she had muscle pain and memory and concentration problems. She was tense, and suffered from anxiety, and her mood became very low. She had a friend who would call around and perform some household chores and bring food for her, without this help, she does not know how she would have managed.

The exposure came to light through chance. New insulation was fitted in the loft, but the installers disturbed a pipe and caused a water leak into Sarah's bedroom. It turned out that the boiler in Sarah's flat been there since 1998, and that there was a further and instantly more serious problem than the age of the boiler. Although there was a flue connecting the boiler and the kitchen ceiling (despite the instructions on the boiler stating that the flue should leave the boiler horizontally and not vertically) taking exhaust gases out of her flat, there was no such connection in the loft itself, leaving the gases free to circulate in the loft space that covered Sarah's and her neighbour's flats on the top floor of their building and, of course, permeate those living areas of the top floor flats. Engineers had been called as Sarah had smelled gas; the man who attended told her that she should count herself 'lucky' as the man who had been initially assigned to this job had a back injury and would not have been able to climb through the loft hatch. His first question, on sharing his discovery, was remarkable to Sarah: he didn't ask about her health, but about whether the loft had been checked by the engineers who had performed the checks and services. He wondered if the engineers on call had said that they were unable to gain access, but the previous safety checks said that they had checked the loft. The problems that he had found instantly had not been noted. Sarah thought, instantly, that this may be the origin of her health problems.

Her friend, a doctor, had found out that her GP could take a venous blood sample to check her levels; at her appointment, four days later, her GP was adamant that he could not, and she had to argue with him until he checked and realised that he could indeed perform a venous blood test. Her neighbour, a woman who had lived in her flat for a long time and had a diagnosis of ME, was also tested and they both had low levels, which would be commensurate with the amount of time that they had been away from the CO (the engineer had, of course, disconnected the gas supply to the property on discovering the problems with the boiler). These levels persisted, as they were both re-tested several months later, which defies current thinking; levels of carboxyhaemoglobin should not persist after the person is no longer exposed to CO. Sarah has bought an industry-standard CO detector, so that she knows there is no CO around her. She has been paying for private hyperbaric oxygen therapy treatments, but at the time of the interview does not feel much better.

Discovering that she had been exposed to CO signalled the start of a battle for Sarah. She had to continue contending with healthcare professionals who had failed to recognise her symptoms and since the discovery were failing to recognise the implications of the exposure, and she had to engage with the issue of redress; yet the housing agency and the gas providers tried, largely, to disregard the matter. Their attitude seemed to be that as no-one had died, it did not seem to matter that Sarah, the tenants who had lived there before and the neighbour had been exposed to CO. This is a *"tooth and nail"* fight, ongoing at the time of the interviews.

# Appendix 8: Pen portrait: Tisha and Ajay

Interview one: lines 1-881

Interview two: lines 883-1987

> Tisha: *“those, traumatic events have created traumatic emotions that have seemed to kind of stay”*
>
> Ajay: *“I feel now, but especially then, that I have a second chance of life? And, er, so to see my mum, or to watch, like, a football game, was, is like, instead of being something to look forward to it was like something amazing? And it was very just overwhelming, with joy?”*

How I met Tisha and Ajay: through a CO charitable organisation

Tisha and Ajay were newly married and back from honeymoon; they had moved into their new flat which, importantly for them, was close to their extended families, and had both started new jobs. Life seemed very good indeed for them both.

Both were taken ill one Sunday morning, resulting in an A&E visit for Tisha, who had collapsed in the bathroom, injuring herself in the process. Unfortunately, paramedics, the A&E department staff, their families, and Ajay and Tisha themselves did not realise at the time what was causing Tisha in particular to be so unwell. She had a common infection at the time and she had experience of fainting before, although there were differences in this episode. When trying to call the paramedics, however, Ajay found that he couldn’t remember basic information required by the 999 operator, such as their postcode or Tisha’s date of birth. Both also felt dizzy and had other symptoms. Ajay put this down to needing some food and worrying about his wife. Tisha was kept in hospital for a few hours that day, while cervical spine damage from the collapse was ruled out and her injuries were treated.

Both were significantly ill by the next morning. Both were very weak, dizzy and vomiting; Ajay had what was described as *“unbearable”* pain in his neck and head. Over the phone, Tisha‘s mother advised her to call 111 for advice. Paramedics were duly dispatched again; this was solely because of Tisha’s suspected head injury the previous day, and this time CO was suspected by one of the paramedics. He called the gas emergency helpline. It transpired that the man who lived in the flat immediately below them had died from acute CO exposure after switching on a faulty gas fire in his living room; CO had travelled throughout the building but was especially concentrated in the dead man’s own flat and Ajay and Tisha’s flat, as the vent from the fire was situated adjacent to their living room and the CO had moved into the vent, along with the heat of the fire.

There are some echoes of serendipity in this account, in that they had a ‘lucky escape’. As the fire had been continually on since at least the Friday in the flat below, their own flat was too warm for comfort, so the windows were opened on two separate occasions, which must have allowed the CO to dissipate somewhat. They had been out on the Saturday and then in A&E on the Sunday, and Tisha’s parents had asked them to spend the evening in their house on the Sunday evening, thus minimising their time in their own home. The paramedics were only re-called on the second day because Tisha had suffered a head trauma on the first; they arrived very quickly, and then it was one of that team who considered that an environmental reason might be the cause of their rapid decline and called the Gas Emergency Helpline. The engineer who came immediately called for evacuation of the whole block, as the levels were so high; the couple were also informed that a police officer who had tried to gain access to the downstairs neighbour's flat would also have died had she entered straightaway.

They received hyperbaric oxygen therapy over three doses, that afternoon and after an overnight stay in hospital. Ajay had high troponin levels (indicating cardiac muscle damage) that subsequently resolved. Tisha has sequelae that affect both her life and her work; she has developed hyperacusis and short term memory issues, for which a further ten hyperbaric oxygen therapy sessions were prescribed. Her MRI indicated white matter damage, and she has been told that potentially other symptoms could develop as a consequence. Both were affected psychologically and emotionally, whether via the medium of exposure itself or as a result of the trauma, it is difficult to ascertain. Certainly, Tisha sought counselling for thanatophobia. They both show marked coping, and have engaged with charitable work; through this post-traumatic growth they have spread awareness of the dangers of CO and found some closure.

Tisha views what happened through the lens of her faith, and has a deterministic attitude towards their suffering. She has had to contend with the thought that she caused their exposure by the actions of a past life. There is a sense of loss, though, that they have lost a sense of security and they appreciate how fragile things can be. Ajay can look at what happened as giving them a second chance at life, and he finds joy in everyday occurrences, expressing resilience.

They were really interesting to view as a dyad – they place great value on the connectedness that they feel between themselves and with their families. They seemed to 'take turns' at speaking really naturally and the conversation between then flowed – it was interesting and I'm really glad on reflection that we did this.

I don't know if they've considered this, but they had essentially the same dose, but they've had different responses. Tisha has to wear hearing aids and suffers pain and discomfort around loud noises; further daily reminders of a trauma.

Finally, I wanted to include Ajay's succinct insight about why CO exposure remains a problem. Tisha was expressing guilt that she had not thought about buying a CO alarm for the flat:

> *A I think people know what it is, but it's em, the importance or the gravitas of having one isn't emphasized? So,*
>
> *T but I'd seen the adverts-*
>
> *A -but that's the point, yeah? (…) I mean that's the thing, it's the importance you attach to it, you know, we all know, you know, it gets hammered into us if we watch TV, that drink driving is not acceptable, right? But it's taken a long time to get there? And it's something that [.] this needs to be eventually to, the similar level so, people are just like, whoa, have I got one? We need to sort it out*
>
> (Lines 1175-1189)

# Appendix 9: Pen portrait: Matt

Interview one: Matt 1-275; Matt and Daisy 275-1212

Interview two: Matt 1214-2640; Matt and Daisy 2641-3441

> *M I’ll be tomorrow like I am today*

> *D then gradually he got back to [.] normal, but normal wasn't normal [..] normal just wasn't normal, it was like as if he'd lost a lot of his memory [.] he was miserable-*
>
> *M -I couldn't do machines could I?*
>
> *D no oo, he was miserable-*
>
> *M -I made you a half coffee half tea didn't I? (Laughs)*
>
> *D he was proper grumpy, real grumpy,*

How I met Matt (and Daisy): Matt saw a press release about my research in a CO charitable organisation’s newsletter and made contact with me through them, as he wanted to take part in the research

Even though I had been studying the complex issues of CO for years by the time I met Matt, I learned more from another perspective from him, as he was working in the gas industry at the time of his exposure so had a slightly different perspective. Like other participants, he has also since gained a great deal of further knowledge.

His exposure happened in 2004, when he was in a void (empty) property with no electrical supply. In order to use a drill, he needed to use a generator, and because he didn’t have the padlock and chain that he often used to secure the generator outside the house, he brought it inside. He knew that this could be dangerous and he knew why it could be dangerous; to mitigate the effects, he worked upstairs while the generator remained downstairs, with the windows open and the door closed as far as possible. He didn’t know how little time he had, though, and he used it for longer than he had originally planned when someone called to say that they were coming to take the generator to another job. When he had helped move the generator out to his colleague’s van and the colleague had departed, he felt very ill indeed. He went back upstairs where he collapsed; although he felt like he couldn’t move and was experiencing extreme sweating (hyperhidrosis), he managed to make his way to his phone and call his wife, who called an ambulance. He told the paramedic that he had been working with a generator, but the paramedic said that he couldn’t smell anything, seeming to dismiss this information. He developed a terrible headache in the ambulance, about half an hour after he first started having symptoms, but the paramedics, he reported, were just flirting with each other and didn’t seem that worried about him. He also told the triage nurse, but the message was not passed on to the doctor whom he eventually saw, who discharged him.

Matt therefore has no official diagnosis of CO exposure, but it is clear that he did suffer exposure. It became apparent to his family very quickly that he was not well and had suffered harm as a consequence. He struggled with unfamiliar tasks, such as operating drinks machines, his memory was affected, and he displayed some uncharacteristic behaviour. He had worked in financial services previously, and reflects that four years before his exposure he was coping with a difficult and complex career, and then he felt that he was really struggling with quite simple tasks. The most burdensome issue for him, though, remains one of anhedonia, which has not ameliorated. He does find this distressing, as he can remember feeling enthusiasm and enjoyment in life and he appreciates that other people see thing differently. He is often very stoical and comments on more positive aspects of his situation; he doesn't feel stress, for instance, which he thinks might be the reason why he never ever has a headache. He did seek medical advice, but was very disappointed and hurt when his GP laughed at his suggestion that he was suffering from the after effects of acute CO exposure.

What I learned from Matt: about the short courses (you can be trained really quickly to 'check' boilers) which can lead to others making serious mistakes because of their lack of training. I learned about the reporting of those who get fined and jailed for not having being gas safe registered but are still fitting/working with domestic gas to save some money and cut some corners. I also learned about the fraud that is committed, so that the general public may, in ignorance but in good faith, be vulnerable to being preyed on by them. Anyone can buy a boiler, and anyone can do any amount of DIY on their homes and there is a significant difference between a service and a safety check. He is very knowledgeable and thoughtful.

He told me about a young man who died from doing the same thing – the coroner recorded an open verdict, as it is not known whether this tragedy was an accident or suicide. It seems that people working in this position should somehow 'just know' about CO, but we don't, no-one does. We don't know how dangerous CO really is and we don't know how easy it is to be affected in the right circumstances.

Daisy was very glad to be involved, which I suggested because Matt had alluded several times to the fact that she would be able to tell me more and that she would have noticed different things since the exposure occurred. Some issues reflect Daisy's view that she doesn't think Matt was in a position to comprehend quite how ill he was. Some issues are presented in themes that are hers alone, during the first stages of analysis. They have different memories about what happened – Matt remembers that Daisy called his older daughter as she was working nearby, and he recalls her being at the void property with the paramedics; Daisy doesn't remember that she was there at all. Similarly, they remember different things about the progression of Matt's symptoms. Daisy recalls how tired he was, while Matt says that he was initially fine. They both recall how he quickly developed memory and motor dysfunction, which manifested itself in situations such as working complex and unfamiliar drinks machines. A poignant example of this was the incident when Matt brought Daisy a coffee with a tea bag in it – a *"half coffee, half tea"*, saying that he couldn't remember what she had asked for. Daisy's husband of many years had also forgotten that she didn't even like tea.

The conversation between them was easy, warm and informative. Sometimes it felt as though Matt was trying to downplay some of his issues or even deflect attention away from them; Daisy, however, would always keep the conversation on track and spoke really directly about the exposure and its effects on the whole family.

# Appendix 10: Pen portrait: Showgirl

Interview one: 1-829

Interview two: 831-2592

> *What do I need to do, do I need to die? Is that what I need to do? Because, would you believe me then, when I'm dead […] or will they put that down to something else?*

How I met Showgirl: through a CO charitable organisation

Showgirl has a pressured, professional job, and suffered CO exposure at the unwitting hands of her neighbour, who seems to use his open, possibly faulty, fireplace (adjoining her property) to dispose of the waste produced in his building job. She has seen him carrying many bits of wood, painted wood, and MDF, presumably with the intention of burning them in the fireplace. She does not think that there is a properly installed chimney breast, and during the period in question (mainly throughout 2017) she could smell smoke inside her property. Smelling the smoke was accompanied by unpleasant symptoms concomitant with exposure to CO. Due to the nature of what she saw being carried through the house, it is reasonable to surmise that this is a case of CO+ exposure. This was confirmed by her contacting me through one of the charitable organisations to ask for a data logger to be sent to her; this did show spikes of CO in her property (see appendix 11), but the dataloggers do not measure any other gas/substance.

Her first symptom was an exacerbation of the asthma that rarely troubles her. Smoke can be a trigger for her, though, and she found that her chest was feeling tight and she was feeling generally unwell – she was aware that she would improve when she left her house, however. One Saturday, she recalls feeling groggy and was aware of her heart pounding; she tried to make herself a cup of tea but found that she had forgotten how. She sent her daughter a text which made no sense; her daughter telephoned her and persuaded her to leave the property. She called the emergency gas helpline who established that her boiler was not a source of a leak. The engineer did find some CO (less than 10ppm) when he stuck a probe into a crack in the wall; despite not finding any in the main rooms of the house, and despite the house being ventilated before his arrival, he did not question this as being anything other than a background level. On another occasion when she felt the same confusion, she went to work but then went to A&E after she had finished. They did a blood gas, which was clear, but she was still ill enough to be told that although CO exposure could not be confirmed, because of the elapsed time, some sort of 'poisoning' did seem to be the cause of her symptoms.

Showgirl talked a lot about how people's attitude to life affects them. She wasn't deterministic, as others have been, rather she took the point of view that the individual is in control; for instance, if someone thinks they are superior to someone else, he or she only has any power over that person if the person agrees and abides by that. She is very much her own person. She enjoys her own company. She refuses to accept pity or see herself as a victim of any sort, despite her ongoing fatigue.

An active, articulate, determined person, she sought help from the Environmental Health Officers, but was dismayed to find that they were unable and, she felt, unwilling to help. The officers who visited her had a significant lack of knowledge about CO, particularly lower level CO exposure and again, only seemed to consider acute, high levels to be an issue, saying that there could not be a problem if her alarm hadn’t gone off. They seemed unwilling to learn from a member of the public. They certainly did nothing that could be seen to be constructive, leading to feelings of powerlessness and frustration.

She has actually had symptoms of fatigue and tingling sensations for many years, but has had other reasons to account for them. She underwent a series of consultations and did have some signs of damage to her white matter that were not commensurate with her age, shown in an MRI scan in 2009. The consultant did not mention this in more recent scans. She did address the issue of CO with him, but she realised that he was discounting the information as he was only considering acute, higher concentration exposure. She reports now, however, that her symptoms are resolving and there seems to be no more smells of smoke coming through from next door, despite the harsh winter of 2017-18.

She became so fearful of living in the house without any support that she spent months staying with her mother and staying with a friend. This was, of course, not sustainable, and she learned that people who had known her for many years found it difficult to accept what was happening to her.

She has managed the situation on her own, and has sought help from several sources, to no avail. She feels that only the charity has been of any real help, and has a sense of bewilderment that more is not widely known about low level, chronic CO exposure.

# Appendix 11 Data logger readings:
## Showgirl’s house (CO readings all in ppm)

| | |
|---|---|
| **04/04/2018 18:05** | 23.5 |
| **04/04/2018 18:10** | 18 |
| **04/04/2018 18:15** | 9.5 |
| **04/04/2018 18:20** | 26 |
| **04/04/2018 18:25** | 15 |
| **04/04/2018 18:30** | 8.5 |
| **04/04/2018 18:35** | 8 |
| **04/04/2018 18:40** | 8 |
| **04/04/2018 18:45** | 8 |
| **04/04/2018 18:50** | 9.5 |
| **05/04/2018 18:50** | 6.5 |
| **06/04/2018 18:50** | 7 |
| **07/04/2018 18:50** | 10 |
| **08/04/2018 18:50** | 6.5 |
| **09/04/2018 18:50** | 7.5 |
| **10/04/2018 18:50** | 11 |
| **11/04/2018 18:50** | 14.5 |
| **12/04/2018 18:50** | 17 |
| **13/04/2018 18:50** | 11 |
| **14/04/2018 18:50** | 7 |
| **04/04/2018 19:45** | 6 |
| **04/04/2018 19:50** | 4 |
| **04/04/2018 19:55** | 7 |
| **04/04/2018 20:00** | 6.5 |
| **04/04/2018 20:05** | 6.5 |
| **04/04/2018 20:10** | 7 |
| **04/04/2018 20:15** | 19 |
| **04/04/2018 20:20** | 27.5 |
| **04/04/2018 20:25** | 13.5 |
| **04/04/2018 20:30** | 15 |
| **04/04/2018 20:35** | 16.5 |
| **04/04/2018 20:40** | 20.5 |
| **04/04/2018 20:45** | 10.5 |
| **04/04/2018 20:50** | 8.5 |
| **04/04/2018 20:55** | 16 |
| **04/04/2018 21:00** | 17 |
| **04/04/2018 21:05** | 14.5 |
| **04/04/2018 21:10** | 17 |
| **04/04/2018 21:15** | 7 |
| **04/04/2018 21:20** | 22.5 |
| **04/04/2018 21:25** | 29.5 |

# Appendix 12: Table 3

## Group one: CO exposure, health and healthcare

| Participants | Reported presenting symptoms of acute CO exposure | Other issues/symptoms resulting from exposure | Others exposed | Treatment for CO exposure | Reported relationship with HCPs | 'Rehearsed' or 'naïve'? | Notes |
|---|---|---|---|---|---|---|---|
| **Bookie** | Confusion, grogginess | Bereaved<br>Has reported psychological difficulties and changes in behaviour/personality* | Mother (died) | Overnight stay in hospital with normobaric oxygen therapy | Generally good, but lack of understanding of potential issues apparent | Partly rehearsed – has spoken to journalists on some occasions | *Would be difficult to distinguish effects of CO from effects of trauma and grief |
| **Vivienne** | Unconsciousness, confusion, incontinence, vomiting, dehydration, anosmia, | Widowed<br>Compartment syndrome to right arm (difficult to say how this was complicated by CO exposure)<br>Complex regional pain syndrome | Partner (died) | HBOT (x3) | Reports excellent care in ITU, but not the case on general ward, where staff were over-stretched.<br>Says GP surgery was excellent and very caring.<br>'Horrific' experience at one pain specialist clinic | Most rehearsed account across all participants – has spent a great deal of time and effort raising awareness through media | |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| **Tisha** | First day: dizzy, syncope, urinary incontinence,<br>Second day: dizzy, headache, tinnitus, nausea and vomiting | Hyperacusis<br>Memory issues<br>White matter damage seen on MRI<br>Has sought counselling for trauma and thanatophobia | Ajay<br>Downstairs neighbour (died) | HBOT (x2)<br>Followed by another course of HBOT (x10) for other symptoms | Good – paramedics identified CO exposure.<br>Both positive about HCP involvement | Partly rehearsed – has spoken to some journalists and has taken part in campaigning work with charity | Interviewed as dyad with Ajay (husband)<br>Both suffered psychologically from the trauma (see Bookie notes above) |
| **Ajay** | Grogginess, dizziness, dazed, pain in neck and head (stated in that order) – unpleasant on first day but becoming unbearable on second. Urinary incontinence, confusion and memory issues<br>Second day, as previous, nausea and vomiting | Raised troponin level | Tisha<br>Downstairs neighbour (died) | HBOT (x2) | See above | See above; same as Tisha | Interviewed as dyad with wife (Tisha) |
| **Matt** | Muscle pain and weakness, hyperhidrosis, collapse and inability to move, headache in ambulance, | Anhedonia, coordination and memory issues, agnosia | None | None | GP laughed at him when he asked whether he could have post-exposure sequelae | Naïve account | Interviewed as dyad with wife Daisy, who was not exposed |

# Appendix 13: Table 4

## Group two: CO exposure, health and health care

| Name and length of exposure to CO | Diagnoses before exposure discovered (coinciding with time of exposure) | Pre-existing condition | Reported presenting symptoms at time CO exposure discovered | Reported symptoms and/or diagnosis post CO exposure discovery | Reported relationship with GP and/or other HCPs | Others in the house (reported symptoms) | 'Rehearsed' or 'naïve' account? | Notes |
|---|---|---|---|---|---|---|---|---|
| **Curstaidh**<br>**Up to a year** | Chest infection<br>Asthma (possibly symptoms were caused/exacerbated by smoking fireplace) | None disclosed | On-going symptoms that seemed to be a chest infection; difficulty breathing, fatigue, persistent, productive coughing (see notes) | None | Very good, although GP did not diagnose CO/did not know about any after effects | Son had headaches and vomiting; treated for migraine but this was discounted. He was to be referred to a neurologist when the CO was discovered | Naïve | CO was partly due to poorly serviced chimney which needed lining, so smoke did not travel out of property effectively (i.e. other particulates may have been contributing to dyspnoea) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Kate**<br>**Three years** | Tietze’s Syndrome | None disclosed | Dizziness, fatigue, inability to focus on and complete usual tasks<br>Chest pain and ECG changes resulting in a weeks’ hospitalisation<br>Nausea, vomiting and headaches on returning to the house after holidays (windows closed) | Agnosia, including agnosia alexa<br>A condition presenting as similar to a stroke or vascular dementia; memory and cognitive issues, and difficulty in retaining information<br>Significant and severe pain in hands, arm, legs, feet – has had nerve release surgery for hands and has a diagnosis of fibromyalgia<br>Has quite severe migraine now<br>Episodes of double vision<br>Susceptible to side effects of medication<br>Significant depression/suicidal ideation<br>Shorter-tempered and less tolerant | Hospital doctors mistakenly thought that she was a cocaine user<br>The specialists she has seen don’t know about CO<br>Not currently under the care of HCPs now, even though she feels that she needs their input due to declining memory | Son had cognitive/learning/memory issues and some GP visits for abdominal pain and headaches. Found to have marked cognitive decline after exposure; has been diagnosed with dyspraxia<br>Work partner had nausea, vomiting and dizziness<br>Husband had enlarged heart and anxiety/panic attacks | Rehearsed – has spoken to press and appeared on television. Does not enjoy this but feels it is an important part of raising awareness. Works with a CO charity | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Be**<br>**Six years** | MSBP<br>Mental health disorder<br>Anxiety/panic attacks | None disclosed | Anxiety and a sense of fearfulness, chest pain,<br>Cognitive issues<br>Memory issues<br>Pain in neck and head*<br>Pain in hands and feet<br>Feeling cold<br>Feeling as though she is receiving ‘electric shocks’ in her body<br>Susceptible to side effects of medication<br>Significant depression with suicidal ideation<br>Hyperacusis and photophobia<br>Self-neglect<br>Balance issues | Organisational skills, cognition and memory issue persist<br>Stiffness of joints | Some GPs, paramedics, and A&E staff she felt were entirely unsympathetic and thought she was malingering or had MSBP | Everyone in household affected slightly differently; all had muscle pain, fatigue, issues with focus, flu like symptoms and some self-neglect in terms of hygiene, etc.<br>Husband had syncopal episodes and issue with sight<br>Oldest child generally unwell, nausea and vomiting/ PCOS diagnosis<br>2nd child had anorexia nervosa<br>3rd child had peripheral neuropathy, hyperacusis significant behaviour changes and school refusal | Somewhat rehearsed; has started to work with charity. Finds speaking about events difficult in some respects due to cognitive issues | *Described as such, rather than a ‘headache’ |
| **Lizzie**<br>**Two years** | Functional Neurological Disorder<br>?Multiple Sclerosis | Vitamin B12 deficiency (diagnosed after CO exposure | Sleep disturbances<br>Syncope<br>Fatigue<br>Balance issues<br>Cognitive issues<br>Memory issues | Symptoms initially largely abated after exposure discovered; overlap, however, with B12 | Disinclined to listen; laughed at her when she collapsed in GP car park | children had nausea, vomiting, diarrhoea and irritability<br>husband ‘looked unwell’ but did not seek medical advice | Naïve | Functional Neurological Disorder considered a psychosomatic disorder; neuro symptoms |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | discovered) | Neuropathy | deficiency symptoms | | | | persist despite no physiological cause found |
| **Sarah**<br>**Three years** | None | Poly Cystic Ovarian Syndrome (PCOS) with insulin resistance | Fatigue (extreme)<br>Affective issues<br>Cognitive issues<br>Memory issues<br>Dizziness<br>Double vision<br>Muscle spasms<br>Feeling cold<br>Anxiety | Symptoms persist; some gradually improving | GPs just wanted her to ‘go away’; she felt that she was perceived as ‘mad and annoying’; one consultant very dismissive of her and angry with her for ‘disagreeing’ with him; another very supportive | None | Naïve | |
| **Showgirl**<br>**?Up to a year** | ?Multiple Sclerosis<br>White matter damage shown on previous MRI | Asthma | Difficulty breathing<br>Confusion<br>Agnosia<br>Memory issues<br>Fatigue<br>Agitation<br>Hypertensive episodes | Fatigue | Generally good; found lack of knowledge about CO | None | Naïve | See appendix 12b for levels of CO recorded in Showgirl’s home |

# Appendix 14: CASP Systematic Review Checklist of Nikitopoulou and Papalimperi (2015)

Paper for appraisal and reference: Nikitopoulou, T.S. and Papalimperi, A.H. (2015) The Inspiring Journey of Hyperbaric Oxygen Therapy, from the Controversy to the Acceptance by the Scientific Community. Health Science Journal, 9 (4), 1-8.

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?
Yes
Comments: clearly focused on title of review, but rather broader in remit than just CO exposure. This is a general review of HBOT and its place in the treatment of various conditions, starting with the 'divers' disease' (Decompression Syndrome, or DCS), including gas gangrene, and continuing with its contemporary uses such as air or gas embolism, radiation injuries, burns, arterial insufficiencies (including diabetic foot complications), complicated fractures and CO poisoning. A full listing of contraindications to HBOT is given with rationale. Authors comment on the lack of RCTs. also clear that the exact mechanism of HBOT's action remains to be established, which has implications for its use.

2. Did the authors look for the right type of papers?
Yes
Comments: Referenced studies addressed the question, largely, from the various areas of specialty. As stated, comments on lack of RCTs, which are acknowledged to be quite difficult in this arena

3. Do you think all the important, relevant studies were included?
No
Comments: The Juurlink et al. Cochrane Library Database Review from 2005 is not in the reference list

4.Did the review's authors do enough to assess quality of the included studies?
Yes
Comments: Studies included all appraised

5. If the results of the review have been combined, was it reasonable to do so?
Not combined
Comments: Results only similar in terms of 'success' of the treatment overall, as well as side effects and contraindications, This is because HBOT use considered over various different conditions

Section B: What are the results?

6. What are the overall results of the review?
Comments: Authors state that new/more research is needed to explore other issues for which HBOT may be indicated; however, they are clear that there are specific indications and it "should be treated with caution"

7. How precise are the results?

Comments: Not precise for many of the conditions, but states 80-85% improvement for DCS outcomes

8. Can the results be applied to the local population?
Can’t tell
Comments: CO exposure and damage caused by CO markedly different to DCS

9. Were all important outcomes considered?
Can’t tell
Comments: Would have liked the Cochrane review about HBOT and CO to have been included: maybe could have been surer

10. Are the benefits worth the harms and costs?
Yes
Comments: Stated to be safe/without side effects with duration and frequency of treatments

# Appendix 15: Participant Information Sheet

Title of Project: Surviving Carbon Monoxide Poisoning 15/EHC/036

Name of Researcher and School/Faculty: Julie Connolly, School of Nursing and Allied Health/Faculty of Education, Health and Community

*You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it involves. Please take time to read the following information. Ask if there is anything that is not clear or if you would like more information. Please take some time to decide if you want to take part or not.*

What is the purpose of the study?

*The purpose of this study is to examine and record the lived experience of those who have suffered a Carbon Monoxide poisoning event. Whilst there is a great deal of literature in academic and scientific spheres about Carbon Monoxide, covering the many different physical symptoms that survivors face, there is nothing from the perspectives of the survivors themselves of what life is like for them since that event. Conversely, not much would appear to be known outside of the academic and health-care spheres about the longer-term effects of acute or chronic poisoning. It is hoped that sufferers of such an event would be given a chance to talk about the issues that they have faced since that event, in their own words, particularly if they have encountered symptoms of a physical/psychological/neurological/emotional nature.*

Do I have to take part?

*No. It is entirely up to you to decide whether or not to take part. If you do you will be given this information sheet and asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw will not affect any of your rights/any future treatment/service you receive.*

What will happen to me if I take part?

*If you do decide that you want to take part, please contact me using the details below so that we can firstly discuss the study in full, and then, if you are happy to proceed, we can arrange a suitable time and location where we can meet up and talk. This will be led by you, as I want to hear about your experiences around the events of the Carbon Monoxide poisoning that you experienced, and any after-effects or consequences that subsequently arose.*

*An audio recorder will be used to document the conversation. I estimate that the discussion may take up to an hour of your time. I would then like to conduct another, similar discussion, if possible. This will allow us to reflect on the previous conversation, and enable the documentation of any further information and clarification of your experiences. This will lead to a rich and in-depth account of your situation.*

Are there any risks / benefits involved?

*It may be anticipated that you may experience some distress, as we will be discussing a difficult and traumatic experience. I would encourage you to share those feelings, with myself but also with the charity that you are already connected with. If you do become distressed, I will stop recording, and we will only resume if that is what you want, when you feel ready to do so.*

*You may, however, find it beneficial to talk to me and express your feelings about your experience – research has long suggested that many participants of studies of this nature do find it helpful to talk about such experiences, as they may feel that they have not been heard in the past (Lee 1993).*

Will my taking part in the study be kept confidential?

*The discussions will take place in a location of your choice, so I would ask that this be a private location so that we will not be disturbed or overheard. I would like you to choose how you will be represented throughout the study, as I will not be using your first name, or anything else that can identify you when it comes to writing about our meeting, so I would like you to choose your own pseudonym/code. This will then be how you are referred to throughout the study.*

*I will keep the consent form that has your signature on it in a locked filing cabinet; I will be able to identify you through that in the event that you decide you would like to withdraw from the study, which you can do at any point. In this way, your identity will be kept private and your taking part remains entirely confidential.*

Contact Details of Researcher:

*Julie Connolly, Faculty of Education, Health and Community, Liverpool John Moores University, 79, Tithebarn Street, Liverpool L2 2ER j.connolly@ljmu.ac.uk 0151 231 4397*

Contact Details of Supervisor:

*Andy Shaw, Faculty of Technology and Environment, Liverpool John Moores University, Peter Jost Enterprise Centre, Byrom Street, Liverpool L3 3AF a.shaw@ljmu.ac.uk 0151 231 2584*

*If you have any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact* ***researchethics@ljmu.ac.uk*** *and your communication will be re-directed to an independent person as appropriate*

Lee, R. M. (1993) *Doing Research on Sensitive Topics,* London: SAGE Publications.

# Appendix 16: Email of LJMU ethical approval

From: Williams, Mandy
Sent: 09 June 2015 10:57
To: Connolly, Julie
Cc: Shaw, Andy; Kane, Raphaela
Subject: Ethical Approval

Importance: High

Dear Julie

With reference to your application for Ethical approval by proportionate review

15/EHC/036 - Julie Connolly, PGR - Surviving carbon monoxide poisoning. (Andy Shaw/Raphaela Kane)

Liverpool John Moores University Research Ethics Committee (REC) has reviewed the above application and I am pleased to inform you that ethical approval has been granted and the study can now commence.

Approval is given on the understanding that:

any adverse reactions/events which take place during the course of the project are reported to the Committee immediately;

any unforeseen ethical issues arising during the course of the project will be reported to the Committee immediately;

the LJMU logo is used for all documentation relating to participant recruitment and participation e.g. poster, information sheets, consent forms, questionnaires. The LJMU logo can be accessed at http://www2.ljmu.ac.uk/corporatecommunications/60486.htm

Where any substantive amendments are proposed to the protocol or study procedures further ethical approval must be sought.

Applicants should note that where relevant appropriate gatekeeper/management permission must be obtained prior to the study commencing at the study site concerned.

For details on how to report adverse events or request ethical approval of major amendments please refer to the information provided at https://www2.ljmu.ac.uk/RGSO/93130.htm

Please note that ethical approval is given for a period of five years from the date granted and therefore the expiry date for this project will be June 2020. An application for extension of approval must be submitted if the project continues after this date.

Mandy Williams, Research Support Officer

(Research Ethics and Governance)
Research and Innovation Services
Kingsway House, Hatton Garden, Liverpool L3 2AJ
t: 01519046467 e: a.f.williams@ljmu.ac.uk

# Appendix 17: Participant Consent Form

PARTICIPANT CONSENT FORM

Title of Research: Surviving Carbon Monoxide Poisoning 15/EHC/036

Researcher's Name: Julie Connolly, School of Nursing and Allied Health, Faculty of Education, Health and Community

I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and that this will not affect my legal rights ☐

I understand that the discussions will be audio recorded and direct quotes may be used in future publications or presentations, however, these will be anonymised. ☐

I understand that any personal information collected during the study will be anonymised and remain confidential ☐

I agree to take part in the above study ☐

All information collected about you during the course of the research will be kept strictly confidential. Any information about you will not be disclosed to anyone. If the results of this study are published no reference will be made to those individuals who took part. However, should you suggest, imply or state that you are involved in specific serious criminal activities (i.e. acts of terrorism, offences against children) then the researcher will inform the necessary authorities.

Name of Participant Date Signature

Name of Researcher Date Signature

Name of Person taking consent Date Signature
*(if different from researcher)*

*Note: When completed 1 copy for participant and 1 copy for researcher*

# Appendix 18: Gatekeeper Information Sheet

*Gatekeeper Information Sheet*

Title of Project: Surviving Carbon Monoxide Poisoning 15/EHC/036

Name of Researcher and School/Faculty: Julie Connolly, School of Nursing and Allied Health/Faculty of Education, Health and Community

*You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it involves. Please take time to read the following information. Ask if there is anything that is not clear or if you would like more information. Please take some time to decide if you want to take part or not.*

What is the purpose of the study?

*The purpose of this study is to examine and record the lived experience of those who have suffered a Carbon Monoxide poisoning event. Whilst there is a great deal of literature in academic and health-care spheres about Carbon Monoxide, covering the many different physical symptoms that survivors face, there is nothing from the perspectives of the survivors themselves of what life is like for them since that event. Conversely, not much would appear to be known outside of the academic and health-care spheres about the longer-term effects of acute or chronic poisoning. It is hoped that sufferers of such events would be given a chance to talk about the issues that they have faced since that event, in their own words, particularly if they have encountered symptoms of a physical/psychological/neurological/emotional nature.*

Do I have to take part?

*No. It is entirely up to you to decide whether you, or members of your organisation, take part or not. You are still free to withdraw at any time and without giving a reason. A decision to withdraw will not affect any of your rights/any future treatment/service you receive.*

What will happen if I take part?

*If you decide that you want to express an interest, please contact me using the details below so that we can firstly discuss the study in full, and then, if you are happy to proceed, we can discuss contacting suitable potential participants.*

*If you do decide to take part, you will be given this information sheet and asked to sign a consent form to agree to act as Gatekeeper and assist in recruitment of participants from your charitable organisation to this study. Once recruited, the participants will be asked to take part in a discussion. This will be led by the participant, as I want to hear about their own experiences around the event of the Carbon Monoxide exposure, and any after effects or consequences that subsequently arose.*

*An audio recorder will be used to document the conversation. I estimate that the discussion may take up to an hour of the participants' time. I would then like to conduct another, similar meeting, where possible. This second discussion will allow the participant and researcher to reflect on the conversation from the first interview, and enable the documentation of any further information and clarification of the experiences. This will lead to a rich and in-depth account of the situation.*

Are there any risks / benefits involved?

*It may be anticipated that participants may experience some distress, as we will be discussing a difficult and traumatic experience. I will encourage participants to share those feelings, with myself but also with those people at the charitable organisation with whom they already have a connection. If participants do become distressed, I will stop recording the interview, and we will only resume if that is what the participant wants, when they feel ready to do so.*

*Participants may, however, find it beneficial to talk to me and express their feelings about their experience – research has long suggested that many participants of studies of this nature do find it helpful to talk about such experiences, as they may feel that they have not been heard in the past (Lee 1993).*

Will my taking part in the study be kept confidential?

*The discussions will take place in a location of the individual participant's choice, so I would ask that this be a private location so that we will not be disturbed or overheard. Participants* *will choose how they will be represented throughout the study, as nothing that could identify an individual will be used; they will be asked to pick a pseudonym or code, and will be referred to by this throughout the study.*

*Consent forms with signatures will be kept in a locked filing cabinet; I will be able to identify participants in the event that they, or you, decide you would like to withdraw from the study, which can be done at any point. In this way, identities will be kept private and taking part remains entirely confidential.*

Contact Details of Researcher

*Julie Connolly, Faculty of Education, Health and Community, Liverpool John Moores University, 79, Tithebarn Street, Liverpool L2 2ER j.connolly@ljmu.ac.uk 0151 231 4397*

Contact Details of Supervisor:

*Andy Shaw, Faculty of Technology and Environment, Liverpool John Moores University, Peter Jost Enterprise Centre, Byrom Street, Liverpool L3 3AF a.shaw@ljmu.ac.uk 0151 231 2584*

*If you have any concerns regarding your involvement in this research, please discuss these with the researcher in the first instance. If you wish to make a complaint, please contact researchethics@ljmu.ac.uk and your communication will be re-directed to an independent person as appropriate*

*Note: A copy of the gatekeeper information sheet should be retained by the gatekeeper with a copy of the signed consent form.*

Lee, R. M. (1993) *Doing Research on Sensitive Topics,* London: SAGE Publications.

# Appendix 19: Gatekeeper Consent Form

GATEKEEPER CONSENT FORM

Title of Research: Surviving Carbon Monoxide Poisoning 15/EHC/036

Researcher's Name: Julie Connolly, School of Nursing and Allied Health, Faculty of Education, Health and Community

I confirm that I have read and understand the information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily ☐

I understand that my participation, and the participation of service users at this organisation, is voluntary and that I, and the service-users, are free to withdraw at any time, without giving a reason and that this will not affect my legal rights ☐

I understand that the discussions will be audio recorded and direct quotes may be used in future publications or presentations, however, these will be anonymised. ☐

I understand that any personal information collected during the study will be anonymised and remain confidential ☐

I agree to take part in the above study ☐

All information collected about you during the course of the research will be kept strictly confidential. Any information about you will not be disclosed to anyone. If the results of this study are published no reference will be made to those individuals who took part. However, should you suggest, imply or state that you are involved in specific serious criminal activities (i.e. acts of terrorism, offences against children) then the researcher will inform the necessary authorities.

Name of Gatekeeper: Date Signature

Name of Researcher: Date Signature

Name of Person taking consent: Date Signature
*(If different from researcher)*

*Note: When completed 1 copy for participant and 1 copy for researcher*

## Appendix 20: Risk Assessment for good practice in lone interviewing

Health and Safety Unit

| | | | |
|---|---|---|---|
| Risk Assessment | | | |
| Building | N/A | Date of Risk Assessment | 05/06/2015 |
| School/Service Department | Nursing and Allied Health | Assessment carried out by | Julie Connolly |
| Location | Tithebarn Street | Signed | Julie Connolly |
| Activity | Semi-structured interviews conducted with participants in a location of their choosing, which may include their home. The subject matter could be defined as having the potential to cause participants to relive difficult memories. | Persons consulted during the Risk Assessment | Supervisors (namely: Phil Carey) |

| | |
|---|---|
| STEP 1<br>What are the Hazards?<br>*Spot hazards by*<br>*Walking around the workplace*<br>*Speaking to employees*<br>*Checking manufacturers' instructions* | The hazards for the participants are that they are being asked to talk about, in detail, a significant and quite possibly traumatic experience in their lives, as this is what the study is addressing. They may feel that my questions are intrusive, or they may become distressed whilst they recount their experiences<br>The hazards for me as the researcher are that I may be working in relative isolation as I collect data during interviews from my participants. This would therefore involve potential physical hazards concerned with a risk of physical threat or abuse, or potential psychological hazards, possibly as a result of violent action or the threat of violent action on the part of a participant, or due to the nature of the information that is disclosed during the interview itself. There is also the possibility that a risk of being in a compromising position; a risk of being accused of improper behaviour of some sort may exist. |
| STEP 2<br>Who might be harmed and how?<br>*Identify groups of people.*<br>*Staff and students are obvious, but please remember*<br>*Some staff/students have particular needs*<br>*People who may not be present all the time*<br>*Members of the public* | The participants may be harmed psychologically and emotionally by recounting their experiences.<br>I may be harmed physically and/or emotionally by the participants' potential actions (physical harm) and discourse (threat of physical harm, or through what is disclosed). |

| | |
|---|---|
| *How your work affects others if you share a workplace* | |
| STEP 3 (a)<br>What are you already doing?<br>*What is already in place to reduce the likelihood of harm, or to make any harm less serious* | The participant information sheet contains information about organisations that would offer help and support to participants who wish to seek assistance; they have already been referred from similar organisations so the idea of seeking help in this way will be familiar to them.<br>I have plans to record the interviews to help with data analysis, so the risks of being accused of any sort of improper behaviour are minimal.<br>I also have plans to return to the participant information sheet and emphasise that they can refuse to answer any of the questions which I ask; they do not have to give a reason for refusing. I will also point out that the contact details of my supervisor are on the form, as is an email address where they can highlight any concerns or complaints about the research process.<br>I will make sure that participants understand that the interview can be stopped if they are worried or upset.<br>With regards to my own safety, I have read the LJMU lone worker policy. I will make sure that someone knows precisely where I am, that I have my mobile phone on me at all times, and that the person who knows where I am will be expecting my call at a certain time to let them know that I'm alright. |
| STEP 3 (b)<br>What further action is needed?<br>*Compare what you are already doing with good* | None |

| | |
|---|---|
| *practice. If there is a gap, please list what needs to be done.* | |
| STEP 4<br>How will you put the assessment into action?<br>*Please remember to prioritise. Deal with the hazards that are high risk and have serious consequences first* | The potential for physical harm – I will ensure that someone is aware of my precise location and will be expecting to hear from me when the interview has concluded.<br>The potential for emotional harm to participants – as discussed above<br>The potential for emotional harm to me – I will be able to discuss matters with my supervisors, and spend time debriefing and in reflection about the experience, without compromising confidentiality.<br>The interviews will be recorded, as stated. |

Review as necessitated by changes.

# Appendix 21: Table 6

## Portion of Curstaidh's interview

| Emergent themes | Transcript | Exploratory comments |
|---|---|---|
| Worry, stress and distress<br>Putting others first<br>Worry, stress and distress<br>Variety of symptoms<br>It can be explained away<br>Unpleasant and/or unsafe environment | 24 blinding headache, all this sort of things, so it was very stressful for me,<br>25 because, obviously you worry about your children anyway, but it was, he<br>26 had a lot of time off during that period, or he would go to school and<br>27 then come home again, er, which was obviously very stressful, for me,<br>28 em, I had, had, a cough and a cold, which turned into a chest infection, it<br>29 was a cold damp house as well, we had other problems with the house<br>30 er, in terms of the, the shower system which was shut down for ages<br>31 and running water and all those sorts of things, er, and it was winter, so,<br>32 you know the, the difficulty was of course, that you know, that coughs<br>33 and colds, and all the rest of it, you're assuming it's coughs and colds, | *Terrible headache/*It's a normal thing, to worry about children; worry about their education and health and it's GCSE year<br>Son is trying – she certainly doesn't think he's playing truant; that there is something significant interfering with his attendance at school despite his wishes to attend – worrying when cause is unknown<br>*Trying to set the scene and convey what it was like brings up difficult memories – is it difficult to talk about? House is horrible*<br>Both of them are ill – suffering due to the effects of CO<br>Unpleasant environment – usual winter ailments mask truth<br>*Emphasis of getting the whole, difficult picture across*<br>Sense of endurance; winter, cold and unpleasant environment endured over a long time |

| | | |
|---|---|---|
| It can be explained away | 34 you’re in a damp house, blah blah blah, and I started seeing the doctor | These seem like reasonable assumptions to make; who is assuming? C/Dr/both of them? |
| | 35 with a chest infection that simply wouldn’t go, which they tested, and it | |
| It can be explained away | 36 wasn’t bronchitis and it wasn’t this, that and the next thing and they | *Playing it down? And so on, and so forth? Frustration that it wouldn’t clear up and an answer couldn’t be found?* |
| | 37 couldn’t really understand it and in the end I was given and inhaler and | *Number of options as to what it could be* |
| Expert versus layperson | told I probably had asthma, the usual sort of thing, em, but what I was | So what was it, this mysterious ‘recurrent chest infection’? Inhaler as don’t know what else to do? |
| | 39 coughing up was black, or very dark brown, rather than green, so it | *Sounds frustrating?* |
| Asking the right questions | 40 wasn’t infected, but I’ve [..] latterly been told that was probably, as | Did they ask about environment? (did they even ask her to describe productive cough??) More assumptions? |
| Putting others first | 41 an effect of what I was breathing in, anyway [..] it was [name of son] I was | *Could have avoided this, perhaps – pause convey difficulty in thinking this – frustrating to think of this* |
| | 42 really concerned about, | |

# Appendix 22: Table 7

## Clusters of emergent themes into subthemes – Curstaidh's interview

| Subtheme 1: Identity and power(lessness) | Subtheme 2: Fear and Frustration |
|---|---|
| Acceptance<br>Bad things happen to other people<br>Complying with authority<br>Empowered by events<br>Expert versus charlatan?<br>Expert versus layperson (if it feels like a migraine)<br>Failing in duty of care<br>Giving power to another<br>Hope for the future<br>Landlord is always right (therefore everyone else is wrong)/landlord's behaviour<br>Overcoming obstacles<br>Powerlessness<br>Putting others first<br>Redressing the balance of power<br>Trusting in another's competence<br>Usually capable and independent | Bad things happen to other people<br>Escape from the landlord<br>Fear of what could have happened<br>Fear of what happened<br>Frustration<br>Helplessness Infecting the residents<br>Others are at risk<br>Risks are common<br>Someone could have been killed<br>Trapped by problems (firefighting – cannot plan ahead to avoid them)<br>Undeserved suffering<br>Unpleasant and/or unsafe environment<br>We didn't know it was CO (articulating fear)<br>Worry, stress and distress |
| Subtheme 3: Misunderstanding the issue | Subtheme 4: Everybody seems to be in the dark |
| CO revelation<br>Definite about cause<br>Is this just normal?<br>It can be explained away<br>Medical model explanation doesn't fit<br>Much more awareness<br>Undeserved suffering<br>Unseen nature of effects of CO as a disadvantage (frustration)<br>Variety of symptoms<br>Wider impact; physical, social, emotional<br>Working hard to find cause | Asking the right questions<br>Chance saved us (role of chance)<br>Complexities in working together – stuck in the middle<br>Constrained existence (numeration)<br>Going through the motions<br>Lack of joined up thinking around CO<br>Safe at home/safe as houses<br>Smoke's a red herring/smokescreen<br>Time and hindsight<br>Time period (beginning and end)<br>Unaware and therefore at risk |

# Appendix 23: Table 8

## Examples of emergent themes/subtheme clusters/superordinate themes

| **Participants** | **Emergent themes** | **Subthemes** | **Superordinate themes** |
|---|---|---|---|
| Curstaidh (two) | Identity and power(lessness)<br>Fear and frustration<br>Misunderstanding the issue<br>Everyone seems to be in the dark | Traumatic experience | Traumatic experience |
| | | No such thing as justice | Power, judgement and justice |
| | | Ignorance and wilful ignorance<br>Revelation<br>Aftermath<br>Other agencies and ignorance of CO | Everybody seems to be in the dark |
| Bookie (one) | The one left behind<br>Horrific scene<br>One bad thing after another<br>Casualty of circumstance<br>No such thing as justice<br>Fellow feeling | The one left behind<br>Guilt<br>Traumatic effect | Traumatic experience |
| | | No such thing as justice | Power, judgement and justice |
| | | Connectedness | Identity and connectedness |
| Kate (two) | You couldn't put your finger on it/Sneaky CO<br>Levels of ignorance<br>Revelation<br>Things that can't be controlled | Traumatic experience | Traumatic experience |
| | | No such thing as justice | Power, judgement and justice |
| | | The struggle to maintain identity following exposure<br>Raising awareness<br>Connectedness | Identity and connectedness |

| | | | |
|---|---|---|---|
| | Personhood<br>Uncertainty | I couldn’t put my finger on it<br>Ignorance and wilful ignorance<br>Revelation<br>Aftermath | Everybody seems to be in the dark |
| Be (two) | Accused and abandoned<br>Fragmented self<br>Catabasis<br>Consequences of not listening/believing<br>Family life<br>Carbon monoxide does not exist<br>Immaterial culture of exposure<br>Material culture of exposure | Traumatic experience | Traumatic experience |
| | | Moral judgement and gender<br>No such thing as justice | Power, judgement and justice |
| | | The struggle to maintain identity following exposure<br>Raising awareness | Identity and connectedness |
| | | I couldn’t put my finger on it<br>Ignorance and wilful ignorance<br>Aftermath<br>Other agencies and ignorance of CO | Everybody seems to be in the dark |
| Vivienne (one) | Wading through mud<br>Ordinary life to aftermath – eidetic pictures<br>Helpful and less than helpful support<br>Drive to change has a noble purpose<br>Becoming multifaceted | The one left behind<br>Guilt<br>Traumatic effect | Traumatic experience |
| | | Loss of power | Power, judgement and justice |
| | | Identity<br>Raising awareness<br>Connectedness | Identity and connectedness |
| Lizzie (two) | CO the game-changer | Traumatic experience | Traumatic experience |

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|---|---|---|---|
| | Dreadful, dreadful times<br>Hope<br>Behaviours and consequences | Invisible woman/”crazy lady”<br>Moral judgement and gender<br>No such thing as justice | Power, judgement and justice |
| | | Connectedness | Identity and connectedness |
| | | I couldn’t put my finger on it<br>Ignorance and wilful ignorance<br>Aftermath | Everybody seems to be in the dark |
| Sarah (two) | Devastating impact<br>Insidious CO<br>This is how I cope<br>Disparate systems | Traumatic experience | Traumatic experience |
| | | Invisible woman/”crazy lady”<br>Moral judgement and gender<br>No such thing as justice | Power, judgement and justice |
| | | The struggle to maintain identity following exposure<br>Connectedness | Identity and connectedness |
| | | I couldn’t put my finger on it<br>Ignorance and wilful ignorance<br>Revelation<br>Aftermath<br>Other agencies and ignorance of CO | Everybody seems to be in the dark |
| Tisha and Ajay (one) | It nearly shattered their lives<br>Losses | Guilt<br>Traumatic effect | Traumatic experience |

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|---|---|---|---|
| | CO unknown and denied<br>Life through a lens of reward and punishment<br>Connectedness<br>The individual and strength | Loss of power<br>No such thing as justice | Power, judgement and justice |
| | | Identity<br>Raising awareness<br>Connectedness | Identity and connectedness |
| Matt (one) | Tragedy and scandal<br>Myriad effects of CO<br>Life after CO | Guilt<br>Traumatic effect | Traumatic experience |
| | | Loss of power | Power, judgement and justice |
| | Changed identity – am I still me? | Identity<br>Connectedness | Identity and connectedness |
| Showgirl (two) | Impact of experience<br>General ignorance in interaction<br>Her own person<br>A nuanced situation | Traumatic experience | Traumatic experience |
| | | Invisible woman/”crazy lady”<br>No such thing as justice | Power, judgement and justice |
| | | The struggle to maintain identity following exposure | Identity and connectedness |
| | | I couldn’t put my finger on it<br>Aftermath<br>Other agencies and ignorance of CO | Everybody seems to be in the dark |

# Appendix 24: Table 9

## Examples of connections between participants and superordinate themes

| Participants | Superordinate themes | Lines from transcripts |
|---|---|---|
| **Curstaidh (two)** | Traumatic effect | *But it did highlight a number of different areas where people just don't have an understanding of the magnitude and the, the [..] deadliness […]* (lines 631-633) |
| | Power, judgement and justice | *It at least it's right now […] … so nobody else can suffer from that and it was never about money anyway, it was about [..] he was wrong [..] and he should not have rented out a property that failed on so many different levels,* (lines 329-32) |
| | Identity and connectedness | *For the sake of a couple of pennies' worth of making something safe, they'll argue that it is and they'll hope that the rhetoric will overtake you [..] er in his case he picked the wrong person, em, but he'd obviously got away with it before, I think [..]* (lines 558-62) |
| | Everybody seems to be in the dark | *I genuinely think that it's an awareness thing that it's just not something that is routinely screened for, in the way that it is in other countries [..] em, and that is an issue – especially cos they had written down, you know, in a damp house, it's a rented house, it's blah blah – all the signs were there [..] but [..] they didn't have the [..] knowledge to be able to – or the awareness to be able to put that all together* (lines 184-90) |
| **Bookie (one)** | Traumatic effect | *I can't get over it, you know, I still keep getting flashbacks and all sorts [..] I thought if I could do any more, you know, but you couldn't* (lines 774-5) |
| | Power, judgement and justice | *It's just that it's gone on for this long, and this long, and that's what's made the worst of it, you know, I still have, everybody- everybody's parents die, and everybody gets over it, you know, I've lost my brother, I've lost mates, I've lost every relative [.] but this one I can't get over me mum because it's [..] the injustice of it* […] (lines 767-70) |
| | Identity and connectedness | *I know what's wrong and they shouldn't be doing it but I've got, that's why I try and tell them, you know we've got to do that and we've got to do that, and that's why I was called Honest* |

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| | | *Bookie and everybody- I was black and white- I've always been black and white [..] and I couldn't tell a lie, if somebody, said what happened, if somebody said, is that, is that what happened last night, and if it wasn't, or whatever, you know, I'd say, I couldn't tell a lie, I'd just, you know, I'd just tell the truth […] and that's why I got on to them, taking my word [..] calling me [..]* (tortfeasor) (lines 1157-62) |
| **Kate (two)** | Traumatic effect | *I used to walk up to the bridge and look over there and I don't know if I want to jump [.] so I used to walk up every day with the dogs and look over, and as I say part of that's on the, on the that's what I was contemplating [..] nobody ever knew this, even my husband didn't know this, so [.] it was a big [.] that's why I've not watched because I didn't want to [.] but it did affect me, it affected me, you know, in a big way […]* (lines 383-7) |
| | Power, judgement and justice | *What they offered, what we got for it, was just, laughable [.] you know if we'd been in America, then it would have been completely different outcome, but not to say that it was the financial side of it is changes how my symptoms, my -you know, how I am, but, I just think it was [.] the severity of what happened wasn't really, wasn't really taken into consideration [.] and then again settling, so early, when you don't know what's going to- how your life's going to pan out and how it affects you, and same with [name of son]* [..] (lines 1341-6) |
| | Identity and connectedness | *It makes you feel [..] again it's the woe is me [..] it's how you look at things, if somebody says you're a victim you become a victim and it's having that mind-set to go actually hang on a minute, no, I'm not a victim in this, em, but again different personalities, you know, some people will, will [.] take on board what's happened to them and it will be that woe is me and I'm sure you'll come across that, whereas I see it as [.] this has happened for a reason, and, and I'm not going to dwell on- I mean I have had a rough time and I'm not saying I've not had my down [.] days [..]* (lines 2432-7) |
| | Everybody seems to be in the dark | *They can't be, sort of, know, have the knowledge for every single thing going [..] you know, and they do have when you go in they do have, they'll grab the, the little book out and start flicking through, and you think, oh! [.] But, again that's what, they are, you know, they're not miracle* |

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| | | *workers, and- but you would just hope that carbon monoxide poisoning, would be one of those things that [.] they do know about [.]* (lines 1248-51) |
| **Be (two)** | Traumatic effect | *I was battling so much that her eyes, just seemed to be rolling kind of thing, she just couldn't get herself going, and I got really, bearing in mind that I, I was completely traumatised what, by being ignored and everything, and this potential, huge danger in my home [.]* (lines 424-7) |
| | Power, judgement and justice | *It comes down to this whole judgement thing, all that they have seen, the whole way through, is that doctors, just judge you, as being neurotic, and, everything but, what is actually going on, em, and then you, you get told that actually, no, erm, there's no long term effects of, of, of carbon monoxide, and you think to yourself, as a, a person with some common sense, how can you actually say, that six years of children being exposed to carbon monoxide at low levels does nothing to them? How can you as a medically trained individual say that?* (lines 860-5) |
| | Identity and connectedness | *I was in no man's land, I did not know where, where to turn to, and then eventually I found, er, I started finding stuff from, the [.] Fire departments, suggesting that any level of carbon monoxide going into a home is not good, particularly where there are children and everything and in that, there, it was a, from, your way, em, em, up country way, there was a Fire Department that CO Gas Safety, where they endorsed them? And that's where I found the telephone number and everything? Where I phoned [name of charitable organisation director]* (lines 1005-10) |
| | Everybody seems to be in the dark | *With the boiler it's either the product of combustion, or it's the flue, it's not a complicated [..] erm, the safety solutions are actually very simple, and it is incredibly frustrating that, erm, you just go, on and on and on and [.] then, you hear all these other stories and you have these other experiences yourself, for everyone, and then to hear people have been doing it for 20 odd years and, still it's like it is? It's very frustrating [.] erm, but heart-breaking at the same time* (lines 4552-6) |
| **Vivienne (one)** | Traumatic effect | *And that was pretty tough, ah [...] erm, emotionally to take, even though to be honest, mostly you know I only learned this really later from a bereavement counsellor, my- my brain was in* |

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| | | *pure survival mode at that time, and it had basically told, my, my, my body and my brain and my heart to just concentrate on surviving* (line 421-5) |
| | Power, judgement and justice | *Because I want to learn from those experience again, just like, you know, we need to learn why did the police arrest me and why they didn't er, em, and so, I wanted all of the incident, to be investigated, er, and not necessarily just the person, on the incident as well, and everything round it,* (line 2950-3) |
| | Identity and connectedness | *J can I ask you about the charity work that you've done and your involvement in raising awareness of the whole, situation?*<br>*V yeah, that wasn't by design, initially, em, although it then became that, I mean [..] although, at the funeral we decided to have a little fund, rather than bringing flowers so we asked everyone to donate some money* (lines 1047-51) |
| **Lizzie (two)** | Traumatic effect | *And I suppose that, I suppose there was an element of it, doom laden, about this, too, aye (sighs) it was a dreadful time [..]* (line 658) |
| | Power, judgement and justice | *Why, they thought, this isn't worth a blood test [.] well, yes, just because, the man has spoken, the man of the house has spoken, we'll just, you know* (line 612) |
| | Identity and connectedness | *When the gas people condemned the fire I was in touch with a, a person er, who was just setting up a charity [..] er, I can't quite remember now [..] I spoke to her several times on the phone, er […] it was, as I say she was just setting up in a charity, I think she actually, when she heard that I [name of career] I think she had a bit of a role in mind for me, but I wasn't well [..]* (lines 206-9) |
| | Everybody seems to be in the dark | *I don't- I really don't think that people er [..] understand [..] that […] I think people see it very much black and white, it either kills you or it doesn't* (line 220) |
| **Sarah (two)** | Traumatic effect | *I was so sick, I mean I was so, so sick, like, wasn't just physical tiredness any more, my brain was really really just not functioning, sorry, it's quite sad to think about it […] I was so sick, I mean I* |

| | | |
|---|---|---|
| | | *was so, so sick, like, wasn't just physical tiredness any more, my brain was really really just not functioning, sorry, it's quite sad to think about it […]* (lines 99-101) |
| | Power, judgement and justice | *I'm just having to fight for everything, tooth and nail, and only that I have the resources, and kind of, happen to know, pretty useful people, that I'm into this, but [.] there's no capacity [..]* (line 619-21) |
| | Identity and connectedness | *That I've fought and fought and fought as soon as I found out, I was just like, this is not ok, someone's gonna, someone's gonna have to answer for this,* (line 352) |
| | Everybody seems to be in the dark | *Even if everybody that found out, if they were poisoned, there's, there's nowhere for them go there actually isn't anywhere for them to get treatment* (line 631-2) |
| **Tisha (one)** | Traumatic effect | *But I didn't think that I was supposed to, survive that [.] but I was, I was upset, I was continually upset, I continually cried about it, even a year down the line, I cried about it, you know [.] if things get too noisy it reminds me of it* (lines 1531-3) |
| | Power, judgement and justice | *One of their PR people had phoned me, while I was at work during the day, and [.] her first question was, who's fault do you think it is?* (line 1789) |
| | Identity and connectedness | *Reminding myself don't let go of that incident because it's shaped, you to how you are now* (line 1535) |
| **Ajay (one)** | Traumatic effect | *We would have, we weren't meant to stay alive, how bad the gas was, we were [.] it's almost miraculous* (line 735) |
| | Power, judgement and justice | *I spoke to the lawyer, and she said well, the only other avenue you can go down, is to claim against the deceased's estate? But the problem you're going to have [.] is that you're going to have to try and prove in court, that you, that he, was aware, that his gas fire was faulty, he was aware that it would cause harm to both himself and others, and he, wilfully, didn't do that, and she said that is very very difficult to prove, because, he's not there to defend himself?* (line 692-8) |

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| | Identity and connectedness | *The emotions that it gave me, was, just generally, er, I felt like I had, I, I feel now, but especially then, that I have a second chance of life? And, er, so to see my mum, or to watch, like, a football game, was, is like, instead of being something to look forward to it was like something amazing? And it was very just overwhelming, with joy?* (lines 438-42) |
| **Matt (one)** | Traumatic effect | *There's nobody knows I'm here! [.] It sort of come to me that, nobody knew where I was [.] you know, and I thought, I don't want to die here, and I thought, what's going to happen, am I just going to have a heart attack or something, that's what I was thinking, I was thinking I was just going to, go at any minute, and I thought, no I don't want to die here* (lines 69-72) |
| | Power, judgement and justice | *Well, yeah, that's why I went the doctor's, wasn't it, but when he sort of laughed at me, I sort of, it just knocks you right down, doesn't it?* (lines 574-5) |
| | Identity and connectedness | *I think I was aware, that things were changing, you know, but like I say with doing the same work, you know, I think there was a few if you went on different things, you know [.]* (1740-1) |
| **Showgirl (two)** | Traumatic effect | *I went to my mum's, which [.] well, without going into it [.] wasn't [.] ideal at all, but, erm, what else was I supposed to do* (line 238) |
| | Power, judgement and justice | *They are very, medical, consultants, it's black or white, really, isn't it?* (line 475) |
| | Identity and connectedness | *I don't care what people think about me, I said and I really mean that, and I don't mean it in a, selfish, I don't care what people think about me, I just, mean, what does it matter?* (line 1330) |
| | Everybody seems to be in the dark | *I said that to her, that's your job, it's your job! Why am I telling you? She said you've obviously done, a lot of research, cos I had it all [.] well I said I have because I've thought I've had to,* (lines 1813-5) |