

Bearing witness to Distress as Breathlessness: A Hermeneutic Phenomenological study

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Thesis submitted in partial fulfilment of the requirements for the
award of Doctor of Nursing

June 2023

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Acknowledgements

Thank you to everyone who has supported me personally, professionally, and academically throughout this project.

Firstly, thank you to all the participants of the study who generously gave their time and were so open and honest; without them there would be no study.

Thank you to my wonderful supervisors Sue and Dan who have been supportive of and open to my vision for the project and throughout this doctoral journey, even if they didn't always see where I was going.

To Susan Crowther and Gill Thomson who expertly led the Online Hermeneutic Phenomenology Course and embedded my understanding, love of and confidence in hermeneutic phenomenology. To the course cohort of 2021, our HP discussions during and after the course were invaluable. Thanks especially to Gill Thomson who took time to guide me with the methodology on several occasions.

Special thanks to Liz Jestico and Bridget Taylor, with whom I have had wonderful HP discussions, fuelling my confidence and love of this methodology.

Thank you to my wonderful Prof Doc colleagues, together we have shared the fun and challenging times of undertaking a doctorate over 6 years whilst working clinically, supporting family and dealing with all that life brings in a global pandemic; we have really shared a unique journey together.

Special acknowledgements to my dear sisters Catherine and Emily who have remained steadfast in their support for me. Thank you to my parents and parents in law who have always been supportive even if they haven't understood the philosophical components of the study. This is especially for Dick who is no longer with us but would have been proud to have a Dr Speakman in the family.

Thank you to my three wonderful daughters: Sophie, Ellie and Izzy who have been patient, long suffering and understanding despite my determination to complete this piece of work over the many informative years it has spanned. And finally, to my wonderful husband Bob who has always believed in me, despite me not always believing in myself and has been by my side from the beginning.

Abstract

This Hermeneutic Phenomenology (HP) study seeks to identify the experiences of Community Respiratory Nurses Specialists (CRNSs) when supporting people with breathlessness by asking the question “What are the experiences of community respiratory nurses when supporting people with breathlessness?”

A purposive sample of 12 CRNSs undertook in-depth interviews via video platform to explore their experiences of supporting people with breathlessness. Analysis of the data was achieved by crafting stories from the transcripts, addressing Heidegger's notions of being-toward-death, thrownness, machination, being-with, leaping in and leaping ahead as solicitude and the state of the uncanny and then attuning to the mood of the interviews. This unconcealed the complexity of care by illuminating both the challenge and burden of bearing witness to distress as breathlessness as well as the phenomenon of fulfilment.

This study brings new understanding of bearing witness to distress, aligning to emotional labour. This has historically been considered a burden for nurses because understanding has been politically driven. Second wave feminism, the work of Isabel Menzies and later Nicky James and the professionalisation of nurses have all contributed to acceptance of this position. Yet this HP study, examining lived experience of bearing witness to distress as breathlessness reveals that when the antecedents of space to process, connection with patients and teamwork are in place, this can be an opportunity for fulfilment for nurses.

I suggest that in reframing emotional labour as emotional connection, a focus on fulfilment could be embedded in clinical practice, nurse education and management when examining the role of nurses across the profession. This could lead to better patient care as well as improved recruitment and retention of nurses. Further research to explore fulfilment as an outcome of implementation of these antecedents could further develop this notion.

Glossary and Abbreviations of Respiratory Nursing terms

Air hunger: the conscious sensation of being starved of air associated with hypoxia and hypercapnia

Alpha-1 antitrypsin disorder: a rare, inherited condition which causes lung and liver problems. Lack of a protective chemical in the body that makes the person much more vulnerable to the effects of inhaling smoke or other toxic materials like dust, fumes, or chemicals

Ambulatory Oxygen: portable oxygen used for exertion

AHP'S: Allied Healthcare Professionals

BOC: British Oxygen Company

CRNS: Community Respiratory Nurse Specialist

DGH: District General Hospital

Dyspnoea: medical term for shortness of breath often described as an intense tightening in the chest, air hunger or work of breathing

Endobronchial valves: Valves that sit inside the airway that are designed to improve breathing for patients who have emphysema

Hot cross bun analysis: simple formulation used in CBT to develop self-awareness of thoughts, emotions, physical state, and behaviour influence each other

Hypoxic: body is deprived of adequate oxygen supply, Oxygen saturations typically less than 92% for people with COPD

IPF: Idiopathic pulmonary fibrosis

ILD: Interstitial Lung Disease

Innogen: portable battery-operated concentrator (converts air to oxygen) delivering a continuous flow of Oxygen

LTOT: Long Term Oxygen Therapy

MDT: Multidisciplinary Team

Oramorph: Liquid morphine used in small amounts to reduce the sensation of breathlessness

Oxygen saturations: fraction of oxygen-saturated haemoglobin relative to total haemoglobin in the blood

NMC: Nursing and Midwifery Council

PR/Pulmonary rehabilitation: a 6-week guided program of exercise and education to equip individuals with knowledge and skills for self-management

Rescue Meds: antibiotics and steroids given to keep by the GP in the event of a flare up of COPD

Refractory Breathlessness: breathlessness that persists despite medical optimisation

Type 2 Respiratory Failure: ventilatory failure where the lungs fail to eliminate adequate CO₂

Ventilation at home (NIV): the use of breathing support administered through a face mask.

Air is given through the mask under positive pressure in order to eliminate excess CO₂

Chapter 1 Introduction

Trapped. That is what breathlessness feels like. Trapped

In the web of uncertainty, bodily doubt, practical obstacles and fear. The deepest fear you can think of. The fear of suffocation, of being unable to breathe, the fear of collapsing, desaturated to the point of respiratory failure. Even if illness descends on you gradually, over many years, there comes a point- probably around the '30 percent of predicted' mark- where high spirits and a positive attitude just can't cut it anymore.

Carel (2016) The Phenomenology of illness (p109)

1.1 Aim of the study

Breathlessness is frightening to experience and can be challenging to witness. In this study I aim to bring this to the attention of the reader, revealing new knowledge as a contribution to nursing research and clinical nursing practice by understanding the experience of witnessing breathlessness. This will be approached by exploring the research question:

'What are the experiences of community respiratory nurse specialists (CRNSs) supporting people with breathlessness?'

Eckersley (2007) contends that although we are physical, mental and social beings we are fundamentally spiritual beings, "psychically connected to our world" (p54). Therefore, exploration of the lived experiences of nurses requires an approach to enquiry that includes this horizon of understanding, calling for a methodology that could surface meanings from 'supporting people with breathlessness'. Thus, hermeneutic phenomenology was the selected methodology.

The aim of this project was to reveal new understandings from participants experiences of supporting people with breathlessness. This informs current thinking about bearing witness to distress and emotional labour for nurses to guide decision making for management, research, clinical work and education in nursing.

The objective was to interview twelve CRNSs and through hermeneutic phenomenological analysis unconceal meanings, beyond the natural attitude¹.

This chapter will guide the reader through the structure of the thesis.

1.2 Structure of the thesis

Having introduced the aims, objectives and structure of the thesis in this chapter, Chapter 2 sets the scene for the background and context of this study. I have chosen to make the focus of breathlessness disease specific due to my current role as a Community Respiratory Nurse. I outline the experience of breathlessness for people living with respiratory disease, those close to them and health care professionals caring for them in order to unpack the research question. I conclude the chapter with my pre-understandings, which set out my position coming to this study in congruence with the chosen methodology of Hermeneutic Phenomenological (HP). As I am part of the interpretive process, my pre-understandings outline my situatedness working in a dialectical way with literature and the data, acknowledging my own position in interpretation as a researcher and practising CRNS interviewing my peers.

In Chapter 3 I review the literature regarding breathlessness and the experience of nursing care. I outline Smythe and Spence's (2012) paper as the framework for the chapter, building on the clinical nursing literature presented in chapter 2 and briefly outline breathing and breathlessness in a historical, anthropological and cultural context. I shed light on the factors that influence how breathlessness is revealed or hidden in wider society, concluding with two poems (appendix 6 and 7) that speak to the emotion of witnessing breathlessness and of caring for others.

¹ The natural attitude is ontic thinking that is subliminal, unchallenged and generally functional unlike a phenomenological attitude which gives a deeper ontological level of interpretation, informed by philosophical tenets, existential and modes of being-in-the-world outlined to draw out what is already known but hidden.

Chapter 4 explores the chosen methodology, philosophy and methods. My own epistemological and ontological position, coupled with the focus of the research question to reveal the lived experience of supporting people with breathlessness identify hermeneutic phenomenology as the methodology of choice. Investigating the experience as it is lived rather than conceptualised reveals meaning that is multidimensional and multi-layered. Exploration of descriptive, hermeneutic and interpretive phenomenological analysis outlines the rationale for the choice of Hermeneutic Phenomenology; to reveal deeper understanding and meaning. The use of Crafted Stories, based on the work of Crowther, Ironside, Spence and Smythe (2016) is explored and justified to present each interview as a whole rather than seeking to reduce, categorise or synthesise the data, allowing immersion in the story told by each participant. I give a brief outline of Heidegger's philosophy of phenomenology and the Heideggerian notions referred to in the project. The methods section considers the ethics process, recruitment, data collection through in-depth interviews and the process of analysis.

Chapter 5 introduces the first part of the analysis: crafting stories. This is a brief chapter outlining how each story was crafted from the interview transcripts, showing the example of Gwen's story. The aim of this is to show how data is not changed through crafting stories, but instead enables the experience shared to be revealed as a continuous narrative. Chapter 6 outlines the second and third parts of the analysis. In the second part I share what was revealed from exploring the Heideggerian notions in relationship with the data, giving a depth of insight into the participants' experience and their challenges of bearing witness to distress (as breathlessness). The third part of the analysis is focused on the attunement of the interviews and sheds a light on the unconcealment of the phenomenon of *fulfilment*.

Chapter 7 is 'into the clearing'; the discussion chapter exploring the implications of the analysis, discussed in a context of the experience of supporting people with breathlessness. The choice of phenomenology as a methodology reveals rich data when focused on participants' experience, that frames the nurse-patient relationship at the heart of therapeutic care. New understanding revealed from participants' experiences demonstrates the

complexity of the lived experience of nursing care: the emotional labour of care that can be distressing but, when the antecedents of 'space to process', connection with patients and teamwork are in place, engaging in emotional labour can also be fulfilling. A new understanding of emotional labour, termed *emotional connection*, is presented that reflects its complexity, identifying that it is not simply engaging with patients' distress that is challenging, it is when the antecedents to fulfilment are not in place that the participants struggled most. The implications for management, clinical practice, research and education in relation to this new knowledge are set out and discussed as recommendations for practice.

Chapter 8 concludes the thesis. In this chapter I reflect on the strengths and limitations of the study, considering my position as a novice researcher undertaking an HP study. I outline the importance of reflexivity in the study and evidence the rigour throughout. I reflect on how this project has changed me, identifying both personal and professional impacts, before concluding the project.

1.3 Research terms clarified

The research terms care, support and witnessing distress are used throughout the study, both in the title of the study and the research question. The outcome of supporting or caring for someone with breathlessness can result in bearing witness to distress. This is in itself an act of caring by offering presence (Cody, 2000). The terms care and support are now examined and discussed, followed by exploration of 'witnessing distress' as they are used throughout the thesis.

Care is synonymous with nursing and refers not only to the practical sense (being with/helping), but in being psychologically and emotionally present (Eusaw and Chick 1999). For CRNSs caring for people with breathlessness, it involves both of these components requiring a holistic approach to clinical practice.

Support can be a noun, verb and adjective and is widely used across fields beyond healthcare but can be defined as ‘the provision of general tangibles... entail[ing] necessary qualities such as individualization... room for verbalising emotions as well as an idea of reciprocal symmetrical exchange between involved parties’ (Stolz, Andersson and Willman. 2006, p1485). Although Stoltz et al.’s definition in their evolutionary concept happens to relate to this specific context when identifying support to family carers of older persons, it resonates with the role of CRNSs when tangibly offering both practical assistance and room for emotional support, that can be reciprocal, in a similar vein to caring.

Therefore, the terms care and support are used throughout this study referring to the holistic approach of CRNSs to people with breathlessness.

Bearing witness to distress (as breathlessness) is the focus of this study, acknowledging the profoundness of breathlessness as a symptom. The term bearing witness is explored extensively in the literature (Naef 2006, Arman 2007, Ceci, Djkwish and Petrovskaya 2020), sometimes relating to suffering (Eifried 2003, Cody 2007), always considering it’s existential position for nurses (Speakman, Butcher and Schutz 2021). The term is used in this study when considering the experience of participants, as they share their experiences of supporting people with breathlessness. It refers to the existential position where participants find themselves as a result of these experiences, unconcealing new understanding through the methodology.

Having introduced this thesis in its entirety, the next chapter examines what is already known about the topic, from both a personal perspective and the published literature.

Chapter 2 Background and context of the study

“As a respiratory nurse, I cared for John Richardson (pseudonym), a 74-year-old man who had end-stage interstitial lung disease... There were no curative treatment options available to him and he was being cared for at home...I supported him and his wife Faye during the last 18 months of his life, regularly visiting them at home. [Nothing] could alleviate Mr Richardson’s severe breathlessness, which constantly reminded him of his disease [severity] and impending death. At the time, I felt that the purpose of my visits was to ‘fix things’ but as his anxiety and breathlessness increased, I felt a growing sense of hopelessness and failure. I struggled with the fact that I could not fix things and began to share the pain Mr and Mrs Richardson were feeling. This was deeply uncomfortable and made me question whether I had become too close to them.”

(Speakman 2018, p28)

2.1 Introduction

This study was borne out of my own experience as a community respiratory nurse specialist, caring for people with breathlessness. I wrote about one such experience in the excerpt above (Speakman, 2018). Reconciling my own thoughts and feelings, I looked to the literature seeking insight into what was known about caring for people with breathlessness, others’ experiences and an understanding of my position in care knowing it was not unique. However, I found little record or insight in this subject area, leaving me with more questions than answers. Therefore, I have completed my own study, shedding light on an important, yet unexplored area of research (Speakman, Butcher and Schutz, 2021). In order to give context and background to this study I have outlined the burden of breathlessness: for people who are breathless, their caregivers and for health services identifying definitions of breathlessness and a brief epidemiology of breathlessness. I then consider a holistic understanding of breathlessness in what is known about relief of symptoms and current

scientific understanding. I explore literature outlining the position of Healthcare Professionals (HCPs) caring for people with breathlessness. I focus on the role of respiratory nurses, more specifically community respiratory nurse specialists because I am doing a Professional Doctorate in Nursing. This study is centred on supporting people with chronic respiratory disease who are breathless (mostly Chronic Obstructive Pulmonary Disease: COPD). In order to give context, the existing literature will be reviewed to consider the burden of breathlessness. With insight into the rationale for the study, the reader is guided through this unexplored area of research.

2.1.1 The Burden of breathlessness

The burden of living with breathlessness for individuals with respiratory disease adversely affects their quality of life (Gysels and Higginson, 2009) and annually costs the NHS £1.9 billion in emergency admissions to hospital and primary care consultations (NHS England, 2020). Hospital admissions for lung disease have risen over the past seven years at three times the rate of all admissions generally (British Lung Foundation -BLF, 2016) making respiratory disease a priority for treatment, care and prevention in The NHS Long Term Plan (2019), the first time that lung disease has been a clinical priority area for the NHS in England. Within the respiratory section of the plan, breathlessness is listed as one of the five main topics of focus, highlighting it as a common symptom shared between people with cardiac and lung conditions (Respiratory Futures, 2022). This acknowledgement of respiratory disease as a priority reflects the challenge that respiratory disease currently ranks globally as the third most common cause of mortality, (WHO, 2016) and the third cause in the UK (BLF, 2016) accounting for 115,000 deaths a year. The challenge of supporting people with respiratory disease was brought into sharp focus amidst the global pandemic of COVID-19. Breathlessness is a symptom experienced by those suffering with moderate and severe COVID-19 and can be a residual symptom experienced in Long Covid (Fraser, 2022). The COVID-19 pandemic has further highlighted the complexity of

breathlessness, where like other conditions including COPD, clinical measurements and disease severity are not accurate clinical indicators of the symptom burden of breathlessness. This highlights the need for further research to better understand its aetiology and alleviate the suffering it causes (Hentsch *et al.*, 2021).

Breathlessness is defined by the American Thoracic Society as

“a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity”

(Parshall *et al.*, 2011)

and chronic refractory breathlessness is defined as

“breathlessness that persists despite optimal treatment of the underlying pathophysiology”

(Currow *et al.*, 2013).

All advancing respiratory disease is characterised by a high symptom burden of breathlessness associated with high use of healthcare and reduced quality of life yet care provision is not comparable to patients with cancers who experience the same symptoms (Booth and Johnson, 2019). Maddocks *et al.* (2017) identified that in most respiratory diseases, especially COPD, once a diagnosis is established and disease progresses, the focus of care remains on disease management rather than symptom management. The trajectory of COPD is long, often many years and as the primary symptoms of breathlessness worsen despite maximal treatment, living with COPD becomes a way of life with an insidious creep of symptoms like cough and breathlessness, (a story with no beginning as it was described by Pinnock *et al.* 2011). This is often accepted by the patient as part of the ageing process and explained by smoking (Oxley and McNaughton, 2016), reinforced as something to be expected by the negative visual representation of people with COPD in the media (Berenyi *et al.*, 2020). Living with unrelenting breathlessness can cause individuals significant physical, emotional, social and economic negative impact to their

lives (Hutchinson *et al.*, 2018). Typically, people diagnosed with COPD come from lower socio-economic classes suffering from other comorbidities such as heart failure and diabetes. As well as reducing the length of someone's life, COPD also has a significant negative impact on the quality of a person's life; simple daily activities such as washing and dressing and walking can be challenging so there is a temptation for the individual to disengage from wider society, especially if living alone (Gysels and Higginson, 2009). This can lead to what McNaughton (2017) described as the 'invisibility of breathlessness' where, due to the nature of the symptom, patients are isolated at home, no longer visible in 'normal life'. Increasing breathlessness can cause fear and anxiety for both patient and caregiver (Johnson and Gozal, 2018), as Carel (2012) explains. As both a Professor of Philosophy and someone who has lived with breathlessness for a number of years, Havi Carel (2014, 2016) writes movingly about her own experiences, acknowledging that:

“respiratory illness is a life sentence with no reprieve”, [that] ‘gives rise to a host of psychological reactions: despair, fearfulness, anxiety, depression, loss of hope’”

(Carel 2016, p110).

The patient's perspective of living with breathlessness has been extensively explored in the literature (Gysels *et al.*, 2008, Hutchinson *et al.*, 2018), highlighting the effect of “total breathlessness” where breathlessness affects every aspect of life (Abernethy and Wheeler, 2008, Lovell *et al.*, 2019) and life is therefore entirely compromised (Kochovska *et al.*, 2020). With an inevitable burden of care falling to those closest, the distress caused by breathlessness on both carers and patients is highlighted in a systematic review by Hutchinson *et al.*, (2018). The complex interplay between patients' and caregivers' coping and help-seeking behaviours around breathlessness potentially adds to a spiral of breathlessness described by Bailey (2004) as *anxiety-breathlessness-anxiety*. Repeated witnessing by the caregiver can lead to “vicarious breathlessness” described by Johnson and Gozal (2018) as a learned fearful emotional response by the caregiver to

breathlessness. That watching loved ones suffer with breathlessness triggered comparative cognitive processes for caregivers was recognised by Herzog *et al.* (2018). This has been identified as a contributing factor to attendance of the emergency department (Hutchinson *et al.*, 2020) where Bailey's (2004) spiral of anxiety and breathlessness escalates perceived care needs. Carel's (2016) experience of living with breathlessness is well described (Tieck, Mackenzie and Lovell 2019, Kauppi *et al.*, 2022, Serresse *et al.*, 2022) but this understanding of the patient perspective has not reflected in clinical practice (Spence *et al.*, 2009, Lunn *et al.*, 2019, Politis *et al.*, 2021).

Most respiratory support services are focused on management of acute exacerbations for people with COPD. There is a recognised deficit in palliative and supportive care provision (Gysels and Higginson 2008) despite the longevity of disease trajectory (Brighton *et al.*, 2021). There are limited pharmacological treatments for breathlessness, and these do not address the psychosocial problems that underlie and perpetuate symptoms (Brighton *et al.*, 2019). Often patients are supported by their life partners or family members who help manage complex medication and oxygen regimens, this can be emotionally stressful and physically demanding (Farquhar *et al.*, 2014). Becoming a 'carer' is challenging for both family members and patients; Tieck, Mackenzie and Lovell (2019) describe the strain it places on relationships with increasing reliance and loss of independence. Kauppi *et al.* (2022) echo the dependence on others and feeling of burden for all those concerned.

2.1.2 Holistic understanding of supporting people with breathlessness

Neuroscience research indicates the complexity of breathlessness, noticeably that markers of pulmonary function do not correlate with severity of breathlessness (Pick *et al.*, 2022). Low mood and anxiety influence interoception (the feedback of senses within the body), prior experience of breathlessness and contextual cues (such as looking at some steep steps and remembering how they induced breathlessness) may result in the experience of breathlessness being heightened (Wilgoss *et al.*, 2012). Left unaddressed, this vicious circle

of anxiety and breathlessness (Bailey, 2004) can exacerbate the experience, leading to help seeking behaviour. Diagnosis with anxiety and depression are often comorbidities that indicate progressive lung disease (Booth and Johnson, 2019).

Ekstrom *et al.* (2022) identified that one third of people attending the emergency department because of breathlessness do not need acute admission. Their study indicates that needs would be better met in the community, yet given the complexity of breathlessness, clinicians report they find it challenging to support people with breathlessness, acknowledging that they do not feel they have the necessary skills or time to support the individual (Spence *et al.*, 2009). Spence *et al.*'s study focused on 23 health care professionals from a range of disciplines including doctors from respiratory teams, palliative care teams and general practice, district nurses and allied health care professionals. They were asked about addressing the palliative needs of people with COPD. They acknowledged that these people were often "crisis managed", losing sight of their prognosis and complex needs mainly due to a lack of confidence in managing breathlessness for this patient group. Fourteen years on, the outcomes of this study were still evident in the study completed by Politis *et al.* (2021) where General Practitioners acknowledge the wide and varied needs of their breathless COPD patients, and their own lack of specialist skills. This gap in skills and referral on to other relevant services often results in people living with advanced respiratory disease without receiving supportive and palliative care to have the best possible quality of life (GOLD, 2017, Maddocks *et al.*, 2017). Breathlessness is often accepted by both patient and clinician as an inevitable part of advanced disease rather than a symptom that needs addressing. These attitudes contribute to and perpetuate the invisibility of breathlessness for patients (Gysels and Higginson, 2008, Oxley and McNaughton, 2016).

Lunn *et al.* (2019) asked trainee Respiratory doctors about their experiences of discussing breathlessness with patients and many admitted they did not want to ask about something they could not fix, are reluctant to ask because of their inability to provide solutions and did not want to "to open a can of worms". This paper acknowledged that the doctor's own

discomfort witnessing the distress of breathlessness is a barrier to its discussion. This research is supported by Barnes-Harris *et al.* (2021) where hospital doctors describe “therapeutic helplessness” and active avoidance of discussion of breathlessness, citing they do not have assessment tools to measure breathlessness or access to the specialist services required to support patients. Grace and Vanheeuvelen (2019) found through their research on HCPs on a Neonatal Intensive Care Unit in an American hospital, that higher status healthcare workers (physicians and nurse practitioners) and Respiratory Therapists (HCPs who specialise in the treat of patients with cardiopulmonary issues) are more likely to suffer with high levels of psychological stress and burnout. The authors align their results with the “stress of higher status” hypothesis (p206). The European Respiratory Society (ERS) has identified understanding of why increased psychological stress and burnout should particularly pertain to respiratory care as a priority for future research to develop multidisciplinary respiratory care (Von Leupoldt *et al.*, 2020).

2.1.3 Respiratory Nurses

The roles of Respiratory nurses are wide and varied supporting patients with specific diseases (Lung cancer/Tuberculosis/Bronchiectasis/Interstitial Lung Disease/COPD/Asthma) in the hospital setting, clinic, Primary care and the community. The majority of work provided by respiratory nurses relates to care outside of secondary care including supporting self-management at home, supporting patients on home oxygen, providing care in the home and facilitating early discharge from acute care environments (Yorke *et al.*, 2017). Yet Yorke. *et al.* identified through their research that most respiratory nursing teams are employed by secondary care trusts and located within acute environments. This is due to financial incentives given to secondary care to ensure all COPD patients are reviewed by a respiratory specialist and discharged with a COPD bundle (Royal College of Physicians, 2017). However, most respiratory nurses provide services that involve chronic disease management out of the hospital (Roberts *et al.*, 2018), reflecting the increasing prevalence

of long-term conditions that are only set to increase (WHO 2010). This integrated way of working of streamlining services provides better integration of services for patients, it is identified as an area for further research by Roberts *et al.* (2018).

2.1.4 Community Respiratory Nurses

Community Respiratory Nurse Specialists (CRNS) work collaboratively with both Primary and Secondary care, providing hospital in-reach as part of their role, to support people with respiratory disease. They may have gained their respiratory knowledge initially in secondary care, laterally moving into community nursing or have established their skills in community nursing (for example District Nursing), gaining their respiratory skills in their community role. Typically nurses who have been qualified for more than five years (Yorke *et al.*, 2017). They may work with Respiratory Medical Consultants in clinics and the community to facilitate specialist care delivery. They will liaise with and advise GPs and Practice Nurses around maintenance treatment options and symptom management and at end of life, collaborate with district nurses and specialist palliative care nurses to advise on and deliver palliative and supportive care. They may support the delivery of Pulmonary Rehabilitation courses by directly delivering the courses or through delivery of education sessions. Generally, CRNSs will meet people towards the end of the trajectory of illness when home visits are preferable to visiting the Practice Nurse at the GP surgery. However, with a condition such as COPD these visits can go on for many years. CRNSs are called upon to offer practical and emotional support and guidance, in their role of supporting people with chronic respiratory disease. The Community Respiratory nursing role differs to that of the Hospital respiratory nurse and the Practice nurse. While these nurses might share the similarities of clinical care for their patients, for CRNS; stepping into the patient's home, the dynamics of the relationship can change (McGarry 2003). The CRNS is a guest in their home and often visits the patient and their family over a sustained period of time, giving them a depth of insight and awareness of individuals' lived experience. Booth and Johnson (2019) recognise

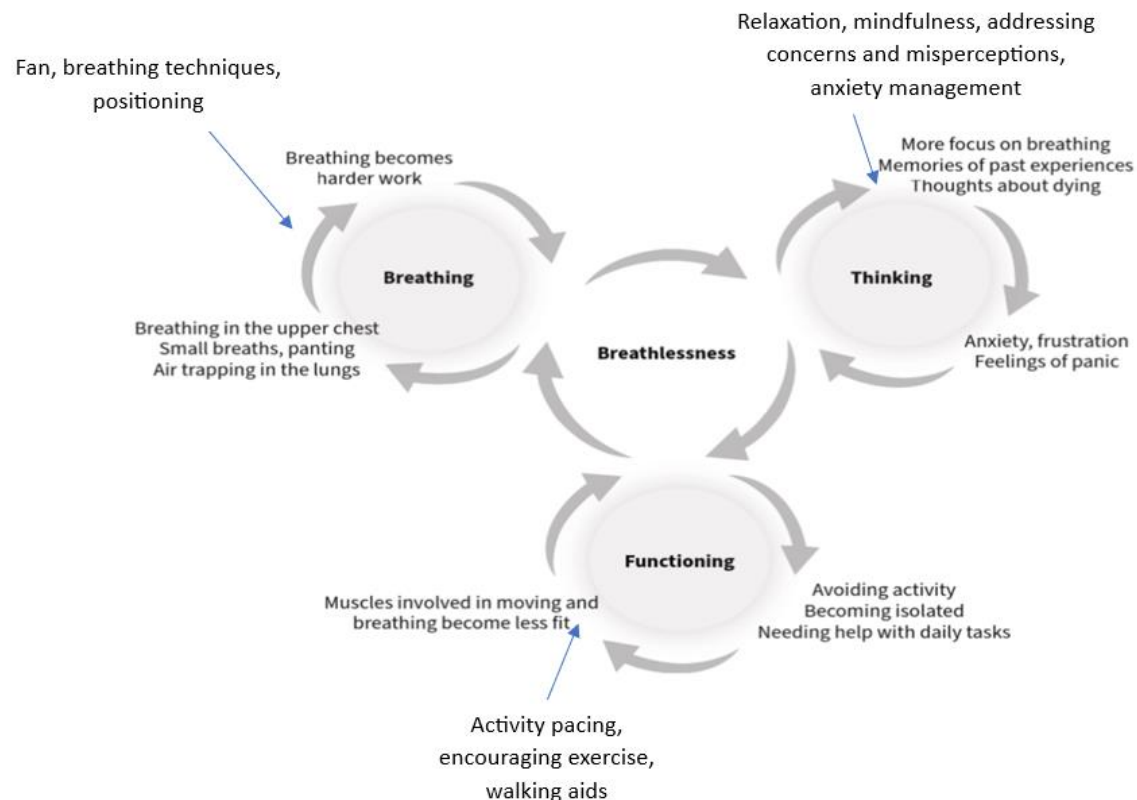
CRNSs as the healthcare professionals providing the most regular support and contact to patients who are breathless, and their families yet Yorke *et al.* (2017) identify there is a paucity of research regarding the role of respiratory nurses, their interventions and effectiveness.

2.1.5 Complexity of care and breathlessness

Care of respiratory patients at home is becoming increasingly complex as people live longer with co-morbidities (WHO, 2010) and CRNSs are increasingly challenged to meet the care needs of this patient group. Ekstrom *et al.* 's (2022) findings that one third of people attending the emergency department with chronic breathlessness do not need acute admission, indicate their needs would be better met in the community. This highlights the need for skilled practitioners to deliver supportive care in the community. Yet pre-registration students and nurses with a special interest in breathlessness often struggle to find relevant post-registration education. Respiratory Nurse education mostly focuses on the mechanics of disease management, effective use of inhalers, smoking cessation advice, the complexities of oxygen requirements and delivery of pulmonary rehabilitation. Respiratory nurses receive little formal training regarding supporting people with breathlessness; learning about the complexity that underpins breathlessness, living with the uncertainty that a chronic respiratory condition brings and acknowledging the end of life, despite this being a significant part of the role.

Spathis *et al.* 's (2017) Breathing, Thinking, Functioning model (Figure 1) is helpful in clinical practice to demonstrate the link in breathlessness between the experience of disordered breathing, subsequent thoughts and feelings that result from this and inevitable inactivity to reduce the experience of breathlessness.

Figure 1 The Breathing, Thinking, Functioning (BTF) Model (Spathis *et al.* 2017)



Key:

→ Indicates intervention to manage this component

While this model offers what can be a helpful practical approach to care, it frames the experience of breathlessness as somehow *fixable* with practical interventions at every point. In reality, as disease progresses this is not the case. The increasing symptom burden of breathlessness, often fuelled by anxiety (Wilgoss *et al.*, 2012) results in “the shrinking of your world, choices, freedom and eventually, your spirit” (Carel 2016, p109). This “dyspnoea invisibility” (Serresse *et al.*, 2022 p7) is an integral part of the lived experience of breathlessness that worsens their burden as people with COPD and

“minimised the severity of their status and considered no help could be provided...participants were particularly frustrated with doctors who they felt were insufficiently knowledgeable about COPD, dismissive of dyspnoea and lacking in relational skills (empathy, communication)”.

(Serresse *et al.*, 2022 p7)

An absence of appreciation by clinicians by demonstrating knowledge and understanding of breathlessness to patients can add to feelings of invisibility. Williams and Carel (2018) suggested that clinicians are assumed to know best yet the desire to constantly focus on the medical model of care can make treatment alienating and intrusive. This suggests that having a lack of knowledge and understanding of breathlessness will be detrimental to the patient experience.

Clinical understanding and management of breathlessness is therefore important; not only to ensure the nurse has the practical skills to support individuals and their families, but because the experience of supporting people with breathlessness, which is a distressing and difficult to treat symptom, can impact the nurse. Latimer *et al.* (2017), considering the experiences of paediatric nurses on ITU, found that repeated exposure to the distress of others, is associated with increased stress and burnout on the nurse. James (1989) and Sawbridge (2016) argue that coping with the distress of others requires ‘emotional labour.’ This could be particularly important in a post-COVID-19 environment where nurses have worked under immense, sustained pressure and witnessed grief and loss both personally and professionally. Engaging with the distress of others has been demonstrated to build trust and a closer relationship (Speakman, 2018) and is likely to be an important but challenging aspect of respiratory nursing. This is therefore an important, yet challenging component in patient care. To witness breathlessness, something so life sustaining and fundamental to our survival as human beings, is to witness distress. Salyers *et al.* (2017) examined the relationship between witnessing distress, professional burnout and safety in

healthcare in their meta-analysis and demonstrated a correlation between clinicians being burnt out and poor patient satisfaction, quality indicators and perceived safety. If these findings are extrapolated to supporting people with breathlessness; it is possible that nurses will be burnt out and patients will be dissatisfied with the care they receive.

2.1.6 The experience of supporting people with breathlessness- current understandings

Little research primarily focuses on the experience of nurses supporting people with breathlessness. The experience of nurses in the more acute care of patients with breathlessness on ICU and at the very end of life in a Hospice are explored (Goodridge *et al.*, 2012, Tarzian, 2000) where distress is witnessed for intense, but for relatively short periods of time. Both these studies demonstrate the challenge nurses experience when caring for people with continuing breathlessness in the final stages of their life. They describe how taxing it is to stay present during suffering because it can evoke such a strong embodied response for the nurse coming to terms with their own mortality, their own taken for granted breathing and their own inevitable death. These descriptions suggest there could be an emotional cost to the nurse of bearing witness to suffering as breathlessness. These studies are discussed in more depth in the Literature review (chapter 3). The limited research found in this field highlights a gap in knowledge and understanding of the experiences of nurses in a community setting caring for people with breathlessness.

There are no studies to date that focus on the experiences of CRNSs supporting people with breathlessness and few that consider the nurse's experience of care for people with any intractable symptoms. However, it is clear from medical research (Herzog *et al.*, 2018, 2019, Johnson and Gozal 2018) that there are vicarious effects on otherwise healthy individuals of witnessing breathlessness. It was shown that to induce dyspnoea has a negative effect on individuals and increases brain responses. This impact of vicarious breathlessness is understood for life partners and those close to the individual but has not been explored in

relation to clinical practitioners. As Von Leupoldt *et al.* (2020) found, understanding of the respiratory practitioner role has been highlighted for future research by the ERS because it is particularly stressful and linked to burnout. Therefore, progressing understanding of the experience of CRNSs witnessing breathlessness will further understanding in this field and identify ways to develop clinical practice.

2.2 Focus of the study

The focus of this study is to explore the experiences of caring for people with breathlessness by CRNSs in order to gain understanding and seek new knowledge of this aspect of their role. The population for the study (CRNSs) was identified by the researcher looking to gain insight into the nurse's lived experience of this role. The specific role of CRNS with the longevity of care of many of their patients puts them in a distinctive and important position to support their patients with breathlessness. New knowledge, focused on nurses' experiences of the role in supporting patients with breathlessness bringing new understanding, might enable the barriers to delivery of holistic breathless management to be addressed so that it is integral in the respiratory care of patients. Understanding will shed light on the antecedents and precedents to holistic breathless management and bring awareness of wider thinking about breathlessness beyond the medical sphere, reflecting more of the patients' lived experience of breathlessness. This unexplored area of research will also give further insight into the experience of caring, reflecting on how through an understanding of supporting people with breathlessness, emotional labour might be a conduit to fulfilment in the CRNS role.

Mirroring the work of Carel (2014, 2016), the use of phenomenology to look beyond the naturalist view brings the subjective, lived experience of supporting people with breathlessness back to each CRNS to reveal new insights. As an integral part of the

research process and in keeping with the HP methodology, I have made explicit my pre-understandings coming into this study.

2.3 Preunderstandings

Smythe *et al.* (2008) recognise that our presuppositions can predispose us to interpret the nature of the phenomenon before we grasp the significance of the phenomenological question. As the researcher, my implicit understandings inevitably shape the outcome of my inquiry. In order to enter and move in the hermeneutic circle (fig 4, p108) from presupposition to interpretation, Heidegger (1962) suggested that the fore-structure of presupposition must be made explicit to understand *being* in general, as the horizon of the distinction (Heidegger 1962, Inwood 2006). We can only get the idea of *being* from *dasein*'s understanding of *being* and therefore understanding *dasein*² (Inwood 2006). Heidegger (1962) suggested that we can only interpret within our own pre- understanding and so meaning is never complete, as our understanding changes and grows, interpretation is always contextual, expandable and expanding.

Heidegger's (1962) notion that we always approach phenomena with pre-understanding and prejudices is framed within the fore-structures of understanding, describing our situatedness in the hermeneutic circle. These are *fore-having*; looking back at practical familiarity with the phenomenon so stating 'already there knowing', *foresight*; giving the present perspective through a professional lens demonstrating understanding so the ability to imagine how it might be and *fore-conception*; the ideas we bring, looking to the future anticipating what will be revealed and anticipating findings. Making these understandings explicit demonstrates my part coming into the study.

² Dasein is explained fully in 4.3 Heidegger's philosophy but essentially it is the situatedness of being human in the world

2.3.1 Fore-having (*already there knowing*):

I come to this study as a nurse researcher and Respiratory Practitioner dedicated to delivering patient centred, holistic care. My undergraduate dissertation considered the role of complementary medicine in nursing practice, and I have always wanted to think beyond the remit of medicine as an exclusive intervention for patient care. I believe nursing can and should offer something different to medicine and can be a therapeutic intervention in itself (McMahon, 1991). Having worked in the community for 25 years, as a District Nurse and now a Respiratory Nurse, I believe caring for someone in their own home puts the power back with the patient to make autonomous choices and receive holistic care.

My interest in supporting patients with refractory breathlessness returns me back to this idea of patient centred care because it is a symptom that challenges every aspect of a person's being. I had an experience with a patient in 2016 (Speakman, 2018) that had a profound impact on me, provoking me to question what being a therapeutic nurse really does entail, what matters to me as a nurse and to the patient/family and can I assist in achieving this? This experience felt uncomfortable but nonetheless important. Caring for someone with severe breathlessness calls upon the nurse to be-with the patient and family unable to “fix-it”, something I struggled with at the time. From this experience I came to understand the concept of being-with and bearing witness to distress and it led me to my research question. I value therapeutic relationships to enable holistic, patient-centred care and feel privileged to be invited into patients' homes and their lives as a CRNS. However, I recognise that relationships between nurse and patient in the community, spanning weeks/months/years can be deeply affecting for the nurse. I recognise that breathlessness is the biggest burden for respiratory patients because once medical management is optimised, it becomes refractory. This is challenging for patients, their family and caregivers. It is also challenging for the nurse because there are few easy fixes or interventions that take away the struggle. I am an emotional, highly sensitive person who strives to be authentic in clinical practice. I

believe these qualities have helped me to connect with patients and while I see these can be positive attributes, they can also lead to vulnerability and burnout.

My desire to use Hermeneutic Phenomenology and seek understanding comes from my personal and professional desires to reflect and focus on experience. This deeply reflective, thoughtful methodology resonates with me as someone who enjoys the free flowing, less constraining approach to research, looking for what lies behind what people say. Through engaging with HP I have become less focused on “fixing it” in both clinical practice and my research and more comfortable with ambiguity and uncertainty.

2.3.2 Fore-sight (*the ability to imagine how it might be*):

I recognize supporting people with breathlessness fits well in the remit of nursing as it calls for wider holistic care, supporting patients medically, emotionally, psychologically, socially and spiritually. Yet my experience shows that nurses support patients in different ways, often focusing primarily on medical management. I see that breathlessness is the biggest symptom burden for our respiratory patients and due to its multifaceted nature, it can be complex. In my experience of practice there is little priority given to equipping nurses with the knowledge and tools for specialist breathless management and therefore rather than confidently meeting the needs of patients who may have severe breathlessness. CRNSs are left to interpret the situation, usually from a disease focused perspective and based on their own thoughts and feelings rather than any comprehensive evidence-based programme. There is some focus in clinical practice on the practicalities of breathless management, offering pharmacological and non-pharmacological interventions to support patients. Yet supporting people with breathlessness could be more than this, taking a holistic approach to addressing the psycho/social/biological/emotional elements of the experience and using ourselves therapeutically to support patients to live with the challenges that their illness brings. I know from working in a team that CRNSs react quite differently to patients with breathlessness which can have implications for individual patients.

I see that some nurses rush to patients with breathlessness: witnessing distress and embracing the situation head on while others remain on a purely functional level, withdrawing from getting close to the discomfort and distress. These differing reactions leave the patient and their family in a precarious position with varying engagement in their care, unable to influence the care they receive from their nurse. Enabling nurses to support people with breathlessness is not currently acknowledged or made explicit so CRNSs will continue to find their own way in this aspect of their role.

2.3.3 Fore-conception (*the ideas we bring*):

Engagement with the literature prior to the study has added to and informed my pre-understandings. I can see that supporting people with breathlessness can be a deeply uncomfortable, challenging aspect of the CRNS role. It is not only about knowledge base of strategies for breathless management, but also about personal, emotional and spiritual wellbeing and feeling supported as nurses to engage in emotional labour. My own stand out experience of supporting a patient with breathlessness was deeply uncomfortable yet I was aware I had witnessed something very profound and important.

Understanding this experience through a Hermeneutic Phenomenology lens has enabled this phenomenon to be explored beyond the 'natural attitude'. I expected that this study would reveal that witnessing breathlessness is a deeply uncomfortable, challenging aspect of our role and that nurses cope with it very differently. I hoped that seeing this subject through the lens of Heidegger's notions might lead to new understanding of the phenomenon of supporting people with breathlessness and in doing so reveal the personal and professional cost for nurses but also the opportunity to improve patient care.

2.3.4 Excerpt from Reflexive diary 9th Sept 2020

"I hope that my study would shed light on this to consider that if we are to engage with and bear witness to distress, our profession should recognise and support us in this. I am aware

that I am very engaged in this subject and while that fills me and drives me to complete this research project, I also hope it will not cloud my opportunities to look at possibilities for interpretation that go beyond my thoughts and feelings on the subject."

2.4 Conclusion

This chapter has outlined the epidemiology of breathlessness in relation to respiratory disease, briefly describing the experience of breathlessness. I have described how the acceptance of breathlessness as an inevitable part of respiratory disease by patients, families and health care professionals alike (Gysels and Higginson, 2008, Oxley and McNaughton, 2016) perpetuates the invisibility of breathlessness (McNaughton, 2017), hiding it in plain sight. It is evident from the literature that clinicians experience discomfort when bearing witness to breathlessness (Spence *et al.*, 2009, Politis *et al.*, 2021), highlighting it as a distressing symptom to witness, impossible to treat and with limited success in managing. This goes some way to explain the barriers to supporting people with breathlessness in practice. The pivotal role of the CRNS has been explored, highlighting it as well placed to support people with breathlessness in their own homes over what is often a long disease trajectory. The complexity of caring for people with breathlessness coupled with the lack of specific evidence in this field, highlights the relevance of this research study to shed light on the experiences of CRNSs supporting people with breathlessness. The focus of this study has been outlined. In congruence with the chosen methodology of Hermeneutic Phenomenology, the chapter concludes with my pre-understandings. Making these explicit as the researcher coming into the study provides an audit trail for the reader, demonstrating my influence on the evolution of the project. This transparency continues in the next chapter when I outline the literature review to offer a wider understanding of breath and breathlessness.

Chapter 3 Literature Review

"Literature adds to reality, it does not simply describe it. It enriches the necessary competencies that daily life requires and provides; and in this respect, it irrigates the deserts that our lives have already become."

C.S Lewis (Holmer, 1977)

3.1 Introduction

In order to remain congruent to my chosen methodology of hermeneutical phenomenology, I have been guided by Smythe and Spence's 2012 paper to present this literature review demonstrating both breadth and depth of thinking regarding breathlessness. Smythe and Spence's premise demonstrates hermeneutic thinking when approaching literature. As they suggest, my personal fore-structures of understanding will be outlined when approaching the key texts and literature that resonate when researching breath and breathlessness.

In chapter 2, context to this study has been given, identifying literature that outlines the epidemiology of breathlessness, interventions to support people, the discomfort of HCPs regarding their role in supporting those with breathlessness and the role of the CRNS. This chapter builds on this picture of breathlessness in healthcare literature, outlining the limited research that focuses on nurses' experiences of supporting people with breathlessness; notably Jellington *et al.* (2016), Bailey, Coella and Mossey (2004) and Tarzian (2000). The search for literature is expanded to look broadly at 'nurses experiences' of care' and outline several further papers that share common themes including the importance of empathy, engagement and relationship, especially when care is provided in the home. The key texts are summarised in table 1.

Following a summary of the gaps in current research that are addressed by the research question, I move on, as suggested by Smythe and Spence (2009), to examine alternative perspectives about breathlessness. The work of the Life of Breath project (Macnaughton and Carel, 2015-2020) is outlined which explored the significance of breath across different cultural contexts, historical perspectives and religious practices. From this I identify how the control of breathing features historically in the ancient practice of yoga to the present day. I briefly explore theatre, literature and music demonstrating how breath is expressed through these forms. As Heidegger identified (1971) in his love of poetry, the sentiment conveyed through the poetic prose can surpass our own simple language, to provoke thinking and extend one's horizon (Gadamer 1976). Examples of poetry are included in the appendix that capture the witness of breathlessness by a psychology professor (Parvan, 2020, Appendix 6) and then a GP's experience of care when she shares how difficult it is to sum up the encounter on a computer system (Rouf, 2020, Appendix 7). I go on to give examples of how the experience of care is shared in poetry and literature before concluding the chapter.

3.1.1 Conducting a Hermeneutic literature review

The aim of this literature review is to provide context and promote thinking by the reader regarding the research question using an interpretive approach to the literature in order to demonstrate congruence with Hermeneutic phenomenology methodology. Guided by Smythe and Spence's (2012) paper discussing the literature review in Hermeneutic research, I have broadened the scope of this review beyond what they describe as a "usual" approach which follows a pre-defined, standard format, completed at the beginning of the study regardless of the methodology used, to include the most recent literature pertaining to the research question. Smythe and Spence suggest that the hallmark of an HP literature review is one that uses literature that spans time, discipline, genres and culture and reveals the researcher's relatedness to the literature that enables them to see the potential insights that lie within; reading in a hermeneutic way is to be attuned and engaged. They cite

Gadamer's position (1975) regarding prejudice: where everyone will prejudge, in this case, literature from their own historicity, thrownness and dasein. In this way literature will be presented from the perspective of the author, constituting the historical reality of their being. Smythe and Spence identify the importance of philosophical literature which draws one into thinking between the lines, shaped by the natural attitude. This philosophical literature encourages the reader to step back from a distance and identify that it is not just what has been said but how it has been said that matters, grasping a new way of seeing.

Therefore, this review aims not only to set the scene for this research project, demonstrate the current knowledge and identify gaps in the field. It will also provoke the reader to consider how historic, cultural and spiritual beliefs about breathing and breathlessness shape subliminal understanding in the present day. The experience of caring and of bearing witness to distress is explored, attuning to insights found beyond nursing literature.

The dynamic and contextual nature of understanding through being in the world is interwoven and inseparable to the language used, our history and culture (Smythe and Spence, 2012). Critically reflecting on these understandings using Gadamer's (1975) back and forth movement or 'play' between tradition and interpretation helps shed light on one's understanding and assumptions. The hermeneutic framework acknowledges the position of myself as researcher and using Gadamer 's appropriation of the term prejudice³, assists understanding in the way these understandings come about.

Smythe and Spence's (2012) guidance to consider Heidegger's (1962) description of our readymade understanding has given ontological insight into my own understanding of my thoughts, expectations and awareness. Making explicit my Fore-having, Fore-sight and

³ Prejudices are referred to in relation to Gadamer's' thinking: "We never approach a subject with "neutrality in the matter of the object nor the extinction of oneself, but the conscious assimilation of one's own fore-meanings and prejudices." (Gadamer 1975, p238)

Fore-conception when approaching the literature puts my own position in the context to demonstrate my situatedness to the reader.

My *Fore-having*, which is already developed understanding of the literature that influences what I encounter and has shaped the research question. It has led me to choose papers that I first encountered when exploring the topic of breathlessness. Most of these focus on the functional aspects of living with breathlessness for patients and carers such as Gysels and Higginson (2011), Spathis *et al.* (2017), Speakman and Walthall (2017) and Booth and Johnson (2019). These give a broad understanding of the functional burden of breathlessness, its financial and emotional costs and the challenge to acknowledge breathlessness as an experience worthy of exploration and further research.

My *Fore-sight* (understanding of what I will find in the literature) has confirmed a focus on the practicalities, but a lack of literature written about the experience of caring for people with breathlessness. This gives an insight into what is already known and prioritised in the literature by authors and journals alike and the need to make explicit the motivation and justification for this research. This has been achieved by looking more broadly at the nursing experience of care as well as exploring the cultural, religious and historical position of breath and breathlessness.

My *Fore-conception* (the idea, already shaped in advance of what will be encountered) as I come to review the literature there is already-there understanding, which is neither right nor wrong but making it explicit uncovers what already exists in my mind. Reviewing the literature after data analysis, and therefore knowing what has been revealed through analysis has shaped the choice of literature showing how understanding links together, what to include and to leave out. I have therefore included papers that move beyond the care as burden and emotional labour narrative to consider the satisfaction and privilege of care, reflecting the phenomenon that is revealed in data analysis.

The explication of my position of understanding approaching this literature review informs the choice of evidence, explores current understanding and the gaps in research. Setting the scene brings the reader to the position of understanding the community respiratory nurse.

3.2 Search strategy

An Integrative literature review approach was used to search for papers within the academic field. This approach, adopted by Whitemore and Knafl (2005), incorporates a breadth of studies including qualitative and quantitative to provide a richer/deeper understanding of the subject, consistent with Smythe and Spence's (2012) requirements for an HP literature review. Three computerised databases (The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed and PsycINFO) were used using the search terms presented in table 1. These terms were selected because they were key words in the title of the thesis and the research question. These databases were chosen because they were felt to provide sufficient means for the searches required. The Boolean search also identified the papers should be peer reviewed, linked full text, written in English, searching title and abstract only with no specific publishing dates. Searching using title and abstract only successfully eliminated papers that included the terms 'care' and 'nurs*' which are ubiquitous in nursing literature.

In addition to database searching, reference lists of retrieved papers were used to identify further relevant literature. Grey literature revealed in discussion with experts in this field, from wider reading around the subject area and suggested by others also added to the body of literature used to inform my literature review. The latter was used particularly when searching for examples from the arts, music, literature and culture regarding the depiction of breath and breathlessness as the chosen databases were not relevant for this variety of works.

The inclusion/exclusion criteria is summarised in table 2 and Figure 2 outlines the process of identifying, screening, eligibility and inclusion that I followed in the Prisma diagram.

Table 1 Boolean Terms

1. Nurs* AND experience
AND
Dyspnoea OR Dyspnea OR breath*
2. Bearing witness OR care OR caring OR support
AND
Experience AND nurs*

Table 2 Inclusion/Exclusion criteria

Inclusion	Exclusion	Rationale
Studies that explore nurse's experiences of supporting people with breathlessness (regardless of aetiology)	Studies that address functional descriptions of care, knowledge and interventions	The focus of the study is on nurses' experiences rather than what they do practically
Studies that explore nurse's experience of caring (beyond breathlessness)	Studies that address students or others who were not registered nurses' experiences of caring	Studies that explored trained nurses' experiences of caring offered similar themes to those identified in the data. (Literature review completed after the data analysis)
	Focus on patients or carers experiences of breathlessness	The focus of the study was specifically focused on registered adult nurses' experiences

Figure 2 Prisma diagram

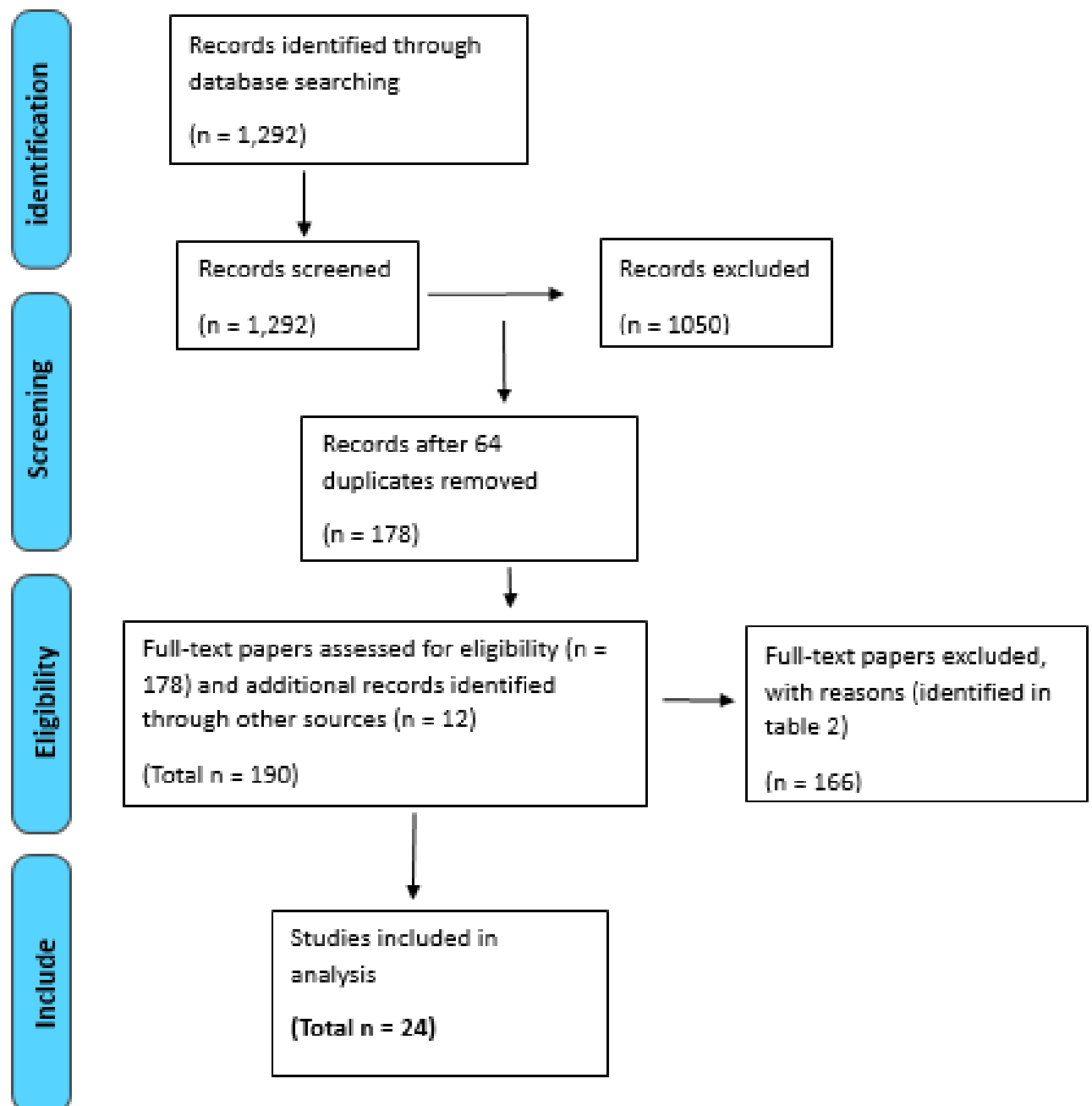


Table 3: Key papers that informed my thinking regarding supporting people with breathlessness

Reference	Research question	Findings	Methods and Methodology	Relevant findings
Jellington <i>et al.</i> (2016) Manoeuvring along the edge of breathlessness: an ethnographic case study of two nurses	Participant observation of 2 nurses' interactions with 6 COPD patients followed by in-depth interviews	Nurses challenged to balance between protecting the patient from breathlessness whilst promoting their capabilities	Ethnography: participant observation and in-depth interview	Experiences of nurses reflect the complexity of supporting people with breathlessness
Bailey, Coella and Mossey (2004) COPD- intuition or template: nurses' stories of acute exacerbations of chronic obstructive pulmonary disease	10 nurses' experience of caregiving for individuals hospitalised during an exacerbation of COPD	Nurses mostly used intuition when caring for these patients, approach was functional with little empathy demonstrated for individuals' experiences of coping with breathlessness	Focused ethnographic narrative	Shaped my awareness that nurses did not always empathise with the lived experience of breathlessness preferring a task orientated approach to care
Tarzian. A.J (2000) Caring for Dying Patients who have air hunger	10 nurses in in-patient settings caring for patients actively dying with air hunger	The experiences of the nurses caring for their patients	Phenomenology analysing interviews with van Manens' guidelines for interpretive phenomenology	Focus on the experience of supporting people with breathlessness, rich insights that encouraged me to understand these experiences in a non-acute setting

3.2 Research focused on supporting people with breathlessness

Research that focused on nurses' experiences of supporting people living with breathlessness due to respiratory conditions that moved beyond the functional description of interventions was limited. However, three papers were identified to be particularly relevant to this study, they are summarised in table 3. These papers consider the experience of breathlessness, and while focusing on nurses' functional approaches to care also explored this experience for nurses. Further papers were identified that supported these studies. Jellington *et al.*'s (2016) ethnographic study considers the nurse-patient interaction in hospital where people with COPD experienced worsening breathlessness. This study explored the challenging role of the nurse manoeuvring between protecting patients from dyspnoea whilst promoting their capabilities. The differing roles of hospital and community nurses is seen in this paper where the hospital nurses' actions are typically more directive than the facilitative role of the community nurse. This study acknowledged anxiety as an important component to living with breathlessness, identifying that people have differing types of anxiety: everyday anxiety and acute, panic anxiety brought on by episodic breathlessness. This study expands upon the work done by Bailey in 2004 that identified the anxiety-dyspnoea-anxiety cycle, which preceded the BTF (Figure 1, Spathis *et al.*, 2017) model but in the same way identified the connection between thoughts and feelings in the experience of breathlessness. When assessing people's breathlessness, nurses referred to their use of pulse oximetry, equating oxygen saturations as a measure of breathlessness, thus confusing hypoxia with breathlessness. The nurses observed patients' experiences of different types of dyspnoea such as exertional dyspnea and gasping, also referred to as air hunger or work of breathing. This substantiates Simon *et al.*'s (2013) study which identifies distinguishable breathlessness types, highlighting that the term "breathlessness" does not

adequately capture the variety and complexity of the experience, an aspect argued by Carel (2014). A nurse in Jellington *et al.* 's (2016) study spoke of her discomfort at witnessing her patient's breathlessness:

"breathlessness that has left them completely out of control. They get anxious, become powerless and have no idea what to do. That's really uncomfortable to watch".

(Jellington *et al.*, 2016, p4)

While this was a small study, only following two nurses supporting six patients, it presented rich data that highlights the nurse's position as intuiting the 'right way' to support patients.

Another ethnographic study, also focused on hospital nurses' experiences, explored nurses' understanding of the care they provided for individuals hospitalised due to acute exacerbations of COPD (Bailey, Coella and Mossey, 2004). The nurses described the "usual behaviours of COPD patients" (p760) recognising that care was often standardised rather than individualised. Nurses referred to patients being predominantly anxious, with breathlessness attributed to anxiety, rather than anxiety being attributed to their breathlessness. Nurses in the study often prioritised technical interventions such as administering oxygen and medicine administration over emotional care. The authors concluded that this study highlighted the importance of individualised patient care and clinical practice informed by new knowledge. It also highlighted how nurses catered primarily to their patients' physical needs and did not engage fully with the patients' distress through breathlessness.

Tarzian (2000) was the only paper found that specifically focused on understanding nurse's experience of breathlessness. Identifying the rationale of the study, Tarzian stated:

“understanding is the first step towards a more consistent and informed response by healthcare providers to dying patients who suffer from air hunger, and to their family members who witness their distress”

(Tarzian, 2000, p137)

This phenomenological study focused on ten nurses working in hospice, long-term care, oncology or emergency medicine settings who cared for patients dying with air hunger. Although the study was referred to as Phenomenology, in reality it was a qualitative study using thematic analysis. This study articulated the nurse's discomfort in supporting people with breathlessness in their last days of life where the death of the individual was imminent. Tarzian (2000) concluded that witnessing air hunger evoked a strong embodied response in the observer, reminding one of our own taken-for-granted breathing as well as one's own inevitable death. Tarzian reflects on Morse *et al.*'s (1992) study, where Morse *et al.* (1992) suggested:

“It is not possible to avoid pain and still be compassionate; therefore, in some situations, feelings of compassion may lead caregivers to withdraw from the suffering patient or shield themselves in order to avoid further pain or emotional involvement”

(p814)

This study concluded that in order to be compassionate, nurses had to be open to their own mortality and suffering. Staying present emotionally as well as physically during suffering demands that nurses “bear witness to distress” (Speakman, Butcher and Schutz, 2021). Tarzian's study corroborated Herzog *et al.*'s (2018) findings of the vicarious effects of breathlessness extrapolated to carers and HCPs. In Herzog *et al.*'s study ‘well’ participants described that witnessing the panic of a breathless patient had a physical effect on them, describing their own shortness of breath or chest discomfort. This challenge of bearing witness was also borne out in Haraldsdottir's (2011) study of Hospice nurses experiences. Haraldsdottir's (2011) findings demonstrated the participants' desire to avoid being-with their

patients, preferring instead to create a cheerful environment. Haraldsdottir (2011) revealed that close association hospice-based nurses have with their dying patients results in an increased vulnerability to their own sense of being-toward-death, and the author concluded that it takes exceptional nurses who are able to bear witness. While Tarzians' (2000) study seeks to explore similar understanding to the present study, there are important differences because it is conducted in an inpatient setting. The focus on inpatient care where experiences were intense but short lived, differs to my study participants. For the participants in the present study, their experiences of supporting people with breathlessness in the community were often with people who experienced a more gradual yet persisting decline and with whom they had long established relationships with individuals. The discomfort of nurses at witnessing breathlessness coupled with the longevity of the relationship is echoed in Pinnock *et al.*'s (2011) paper entitled 'Living and dying with COPD'. A nurse (unclear if it is a Practice nurse/Specialist nurse/District nurse) caring for people with COPD shared:

"We know them so well, and we've always been able to do something, and then it's that part where for the rest; literally what can we do?"

(Pinnock *et al.*, 2011, p6)

This quote captures the feeling of impotence for the nurse when looking to provide support, keen to keep 'doing or fixing'. When there are no more practical interventions to offer this is not only hard for the patient, it is hard for the nurse too.

Yorke (2014) concluded her paper focused on breathlessness interventions, that breathlessness is rarely managed as well as it could be in the community, a sentiment echoed by other authors (Hutchinson, 2018, Booth and Johnson, 2019). This is important to address as supporting people in their own homes is often identified as the best place to care for people with breathlessness (Ekstrom *et al.*, 2022). Seeking understanding through research for the reasons this is the case, will progress clinical practice and patient care.

There are a handful of papers focused on nurses' experience of caring for patients with breathlessness in inpatient settings but there is a lack of research focused within community nursing. Exploration of literature regarding the experience of nurses caring more generally for people in a variety of settings was sought to enable awareness of the lived experience of caring and highlight the valuable insights of phenomenological study of the experiences of nurses and their implications for patients.

3.2.1 Research focused on the nursing experience of caring

With limited research located on the nurse's experience of breathlessness management, the literature review was broadened to include the "nurse's experience of care" more generally. The search terms used are outlined in table Papers that focused on "nursing experience" that relayed common themes about the importance of empathy, engagement and relationship, especially when care was provided in the home were identified. These papers are summarised in Table 4. Accounts of nurse's experiences of care included encounters in home care (Larsson Gerdin, Hellzén and Rising-Holmström, 2021) caring for children with burns (Hilliard and O'Neil, 2010), managing vulnerability when working with seriously ill children (Nugent, Donohue and Higgins, 2022) and accompanying patients dying during the COVID-19 pandemic (Castaldo *et al.*, 2021). Hilliard and O'Neill (2010) recognised the personal impact on the nurse of witnessing distress where participants spoke of hiding their emotions to avoid upsetting the children by physically putting on a mask or creating a barrier to shut out the distress of the child. Participants refuted the idea that the barrier meant they were immune to the child's pain. It was created to disguise the nurse from displaying their true emotions. Nurses experienced anguish for participants when they were unable to relieve the children's discomfort:

"I think some of the most difficult parts for the nurse is the helplessness... that sometimes when a child is crying in pain and you've run out of all option, you feel helpless"

(Hilliard and O'Neill, 2010, p2910)

Table 4: Key papers that informed my thinking regarding nurses' experiences of caring

Paper	Research question	Findings	Methodology and Methods	Relevant findings
Nugent, Donohue and Higgins (2022) Nurses' experiences of managing vulnerability when working with seriously ill children	To explore 5 paediatric nurses' experiences of caring for children who are seriously ill: gaining insight into the dynamics and nurses' experiences of managing their own vulnerability	Nurses felt 'emotionally full', this was exacerbated by short staffing, lack of protected time to debrief and compromise in their ability to care when unforeseen incidents arise	Interpretive Phenomenological Analysis, in depth interviews	Lack of time to debrief and short staffing resonates with my interview data as a burden for nurses when processing challenging situations
Castaldo <i>et al.</i> 2021 Nurses' experiences of accompanying patients dying during the COVID-19 pandemic: A qualitative descriptive study	To explore 31 nurses' experiences of caring for patients dying without family during COVID pandemic.	Emotional distress experienced by nurses who provided holistic care to their dying patients	Qualitative, descriptive design, focus groups	Example of nurses expressing positivity amongst adversity where there were positive outcomes
Gerdin, Hellzén and Malin Rising-Holmström (2021) Nurses' experiences of encounters in home care: a phenomenological hermeneutic study	To illuminate the meaning of 11 nurses' lived experiences of encountering patients in home care.	Home care is both emotionally demanding and rewarding. Being in relationship and trusted by the patient left the nurse feeling safe, secure and receptive to their patient's needs, giving the nurse energy. There was less work stress when nurses had professional experience and felt secure in themselves	Hermeneutic Phenomenology, interviews	Balance of challenge and reward that echoed my findings and my own experience

Hilliard and O'Neil (2010) Nurses' emotional experience of caring for children with burns	To explore the emotions expressed by children's nurses when caring for children with burns, and how they dealt with those emotions	There is a personal impact for nurse who hid their emotions from the children. However, there was a buffer against this distress when children recovered, knowing they had helped	Phenomenology	Complexity of witnessing distress aligns with my own findings and personal experience
Life of Breath Project 2015-2020 Havi Carel and Jane McNaughton, Wellcome Trust	Integration of biomedical research with cultural, literary, historical and phenomenological research	Whilst the physiology of breathing is understood, an holistic understanding of the of breathlessness enriches and deepens our understanding	Variety of methodologies used throughout the project	This project started me thinking about recognising the multi- faceted nature of breathlessness. Creative approach encouraged deep thinking

These feelings of distress are echoed by Nugent, Donohue and Higgins (2022) who considered the experiences of nurses caring for seriously ill children. The emotional toll was felt when nurses described being 'emotionally full', through unprocessed grief that can lead to burn out or a cycle of action that affects their ability to act in an empathetic and supportive manner. The authors highlighted how short staffing and the lack of protected time for debriefing after traumatic events exacerbated the situation for nurses. The nurse's anguish and distress were further exacerbated when extenuating circumstances meant their provision of care was compromised. Castaldo *et al.* (2021) explored nurses' experiences of care and death in Italy in the COVID-19 pandemic. Social distancing in an attempt to limit the spread of infection, nurses had to modify end-of-life care practices without the presence of relatives, often feeling alone and inadequately prepared. The unpredictability of death, high mortality rates, and compromises to care had a detrimental impact on the nurses' psychological well-being.

The nurses' distress was however balanced by the reward of providing care that enabled positive outcomes. Hilliard and O'Neill (2010) described the satisfaction participants felt when patients recovered and left hospital, knowing they had helped children emotionally and physically. This buffered the emotional distress of the role. Larsson Gerdin, Hellzén and Rising-Holmström (2021) exploring nurses' experiences of caring for patients at home, concluding that having a relationship and experiencing the patient's trust helped the nurse feel safe, secure and receptive to patients' needs, giving the nurse energy. Having professional experience and feeling secure in themselves was identified as reducing their work stress and promoting feelings of competence in the patient encounter. As the nurse's vulnerability lies in their engagement in caring for their patients, a relationship built on trust enables nurses to be where the patients are (Larsson Gerdin, Hellzén and Rising-Holmström 2021). The experience of caring will be explored in more detail in Chapter 6.

3.2.2 Summary of the literature and gaps in the research

The limited literature focused on supporting people with breathlessness frames this experience for nurses in an inpatient setting as challenging and deeply uncomfortable (Jellington *et al.*, 2016, Bailey, Coella and Mossey, 2004, Tarzian, 2000). The experience of caring by nurses shares common themes of empathy, engagement and relationship and when there are positive care outcomes, a good relationship and the nurse has professional experience, nurses often feel rewarded by the care they provide. Little is known about the experience for nurses of caring for people with breathlessness in the community where nurse-patient relationships are typically longer than those in inpatient care. This, coupled with evidence of the discomfort of witnessing breathlessness for nurses highlights a gap in research which will be explored by this project.

The subject of breathing and breathlessness and the experience of nursing care is presented in this literature review from a UK perspective, seated in a western context. Wider understanding is gained by exploring literature beyond the healthcare context to provoke a breadth of understanding of our connection with breath.

3.3 Wider thinking about breathing

The experience of breathlessness is rarely discussed outside of healthcare leading to the challenge of describing it subjectively and culturally. Its debilitating nature means that people with severe breathlessness are generally unable to go out, staying hidden behind closed doors. Those with mild to moderate breathlessness, work hard to mask the severity of their symptoms, making it an “invisible” burden (Macnaughton, 2020). This lack of visibility of breathlessness results in limited understanding, awareness and engagement with those who experience breathlessness reinforcing the isolation and distress experienced. Breathing is the only physiological function that can be controlled or manipulated consciously overtaking autonomic, reflexive control. The experience of breathing can therefore be a juncture of the

body and mind so in considering the ontological experience of breath, an awareness of its complexity must be appreciated. While this focus somewhat moves away from the focus of the research question “What are the experiences of community respiratory nurses in caring for patients with breathlessness?”, addressing the notion of breath and breathing gives a context for taken for granted understanding. In looking beyond the medical literature for accounts of breathing and breathlessness, I intend to move away from the reductive, clinical perspective to consider how breath is depicted in the arts, literature and humanities. The Life of Breath Project (Macnaughton and Carel, 2015-2020) sought to take an interdisciplinary approach to answering such questions of what does breathlessness feel like? How do our thoughts, emotions and beliefs affect our breathing? And why do people hide their breathlessness? The project’s collaborative approach to a broader understanding of breathing has enabled an opportunity to consider the wide and varied components of breathing. As part of this project Oxley and Russell (2020) explored the significance of breath across many different cultural contexts, across thousands of years of history looking at indigenous and ancient cultures, western and eastern religions, ritual ceremonies and working practices. Breath is a ubiquitous term that humans equate with life and living in the same way that the absence of breath equates with death. As Oxley and Russell (2020) state:

Breath is a key concept with which to understand the lived reality and substance of soul and spirit, and in doing so can be significant to reveal what it means to be alive or to be human

(Oxley and Russell, 2020, p10)

Understanding the meaning and significance of breath within different cultures deepens understanding beyond the healthcare evidence base to broaden thinking, considering the contexts in which it is appraised and enacted. What constitutes breath remains primarily in the domain of clinical sciences, limiting thinking to the mechanisms of breathing, the aetiology and experience of disease and possible ways to support people with

breathlessness. Macnaughton (2020) highlighted how the medicalisation of breathlessness extends to the language used (calling it dyspnea), so that a lack of non-clinical language of breath limits expression and articulation of the lived experience. Understanding of the experience, how breathing is framed within society and the assumptions made, gives insight into our own subliminal thoughts, feelings and ideas that frame thinking about breathlessness both in clinical practice and more broadly in society.

In western Jewish and Christian traditions, the concept of breath is manifest as the Holy Spirit of God hovering over the waters (The Holy Bible, Genesis 1:2) and 'breathing life-giving breath into the nostrils and the man began to live' (The Holy Bible Genesis 2:7). This awareness of breath being life-giving and as The Spirit of God demonstrates understanding of its fundamental significance to life. Many traditions consider the wind as the breath of God that gives life, considering that breath, soul and spirit are often correlated in understandings of life. For the Khoisan people of South Africa, when we breathe the wind in and out, we are breathing in and out the soul. It is the wind that works the heart (Low, 2007). At death, the idea of the soul being released by the body in the last breath has led to various techniques to keep the soul in the body; Frazer ([1922] 2000) cited by Oxley and Russell (2020) details how for the Marquesans and New Caledonians it was common practice to hold the nose and mouth of those who are dying to continue life and prevent the soul departing. Such is this belief of the power of breath that in the Dinka Tribe (East Africa), the clan chief cannot be allowed to die of natural causes but must be suffocated (usually buried alive) so that the life force in his breath can permeate to the whole community, rather than being lost.

The spiritual connection of breath and body is exemplified by the eastern traditions of Qigong, Tai Chi and Yoga. Their goal is to regulate breath to focus on balancing mood, connecting the mind, body and spirit to reach enlightenment whilst stabilising health. Prana, which literally means 'breath' or the 'breath of life' is more than just breath, it is considered the vital force of life. The yogic control of prana is called pranayama, a complex and

rigorous discipline. These techniques, now widely recognised as beneficial for people with respiratory disease, demonstrate for Eastern cultures a conscious understanding of the body as breath with a rhythm that must be managed and worked on. This challenges the traditional Western understanding that breathing, like many physiological functions, goes unnoticed until there is some breakdown or failure in physical health. Leder's (1990) concept of dys-appearance, drawing on Heidegger's analysis of the tool (1962), is supported by Benner's interpretation of Heidegger's notion of the body as unready-to-hand. It presents the body as only noticed in a dysfunctional state. Recognising the benefits of active breath control is an integral part of the Wim Hof Method (2020) shown to change the blood chemistry and improve the outcome of many inflammatory diseases. Many of the techniques come from ancient wisdom, lost or forgotten in western traditions but hugely beneficial to our health and wellbeing (Nestor, 2020). The notion of breath was brought into sharp focus following the death of George Floyd in Minneapolis in 2020. His dying words "I can't breathe" repeated 27 times from his chokehold remains the strap line for the Black Lives Matter movement representing the feeling of those oppressed by inequality of opportunity. The video footage shown in the prosecution trial of the former police officer, showing Mr Floyd's death as gasping for breath evoked outrage and distress around the world. Breathlessness was further brought into public consciousness with the Covid-19 pandemic. Previously fit and healthy people were struck down, many of whom died experiencing breathlessness that was frightening and debilitating. For many, living with Long COVID, unexplained breathlessness persists as one of many challenging symptoms that have become a new way of life (Fraser, 2022). The enforcement of mask wearing meant we were all thrown into a consciousness of being protected from airborne threats as well as our desire to breath unhindered.

This awareness of breath has been further expressed historically in the theatre, literature, art and music. In Latin "to breathe" (*spiro*) also means "to be poetically inspired", connecting breath and creativity "to inspire" the reader. As the Latin saying goes, *dum spiro spero* ("as long as I breathe, I hope").

Breath is used by Shakespeare in expressing death by the absence of breath in *Henry IV* part 2 IV.iv: Prince Hal sits by his dying father's bed, and mistakenly thinks he is dead:

"By his gates of breath

There lies a downy feather, which stirs not:

Did he suspire, that light and weightless down

Perforce must move. - My gracious lord! My father! "

(Shakespeare, 2013 Part 2 4.3:150)

In *King Lear*, (particularly pertinent as Lear himself has an attack of breathlessness during the speech) Lear carries in his dead young daughter in a very emotional, dramatic speech ending with him dying of a broken heart:

"And my poor fool is hanged! No, no, no life!

Why should a dog, a horse, a rat, have life,

And thou no breath at all? Thou'lt come no more,

Never, never, never, never, never! -

Pray you undo this button: thank you sir -

Do you see this? Look on her, look, her lips -

Look there, look there! [Lear dies]"

(Shakespeare, 1994 5.3:306)

In *Othello* Act V, scene II before he smothers Desdemona; Othello sees her asleep in bed and kisses her, and says

"O balmy breath, that dost almost persuade

Justice to break her sword!"

(Shakespeare, 1992 5.2:15)

In *Romeo and Juliet*, Juliet speaks to her nurse with urgent anticipation in Act 2 scene 5:

*"How art thou out of breath when thou hast
breath. To say to me that thou art out of breath?"*

(Shakespeare, 2002.2: 5: 3)

In *Sonnet 130* Shakespeare describes the breath of his mistress with honesty and without pretence, referring to her breath evocatively:

*"And in some perfumes is there more delight
Than in the breath that from my mistress reeks."*

(Shakespeare, 2008 p640 line 8)

In *The Merchant of Venice* Shylock uses breath to describe his anticipation of what is to come:

*"Shall I bend low and in a bondman's key, with bated breath and
whispering humbleness."*

(Shakespeare, 2000.1: 3: 7)

The term bated, shortened from abated, means 'stopped or reduced', so the phrase refers to those holding their breath in excitement, fear or strong emotion as they wait to see what happens next. This term is also used by Mark Twain in *Tom Sawyer*:

“Every eye fixed itself upon him; with parted lips and bated breath the audience hung upon his words, taking note of time, rapt in the ghastly fascinations of the tale.”

(Twain, 2008, chapter 23)

Milton uses breath and breathing fresh air to depict the contrasts of freedom and oppression in his poem *Samson Agonistes*:

*"A little onward lend thy guiding hand
To these dark steps, a little further on;
For yonder bank hath choice of Sun or shade,
There I am wont to sit, when any chance
Relieves me from my task of servile toil,
Daily in the common Prison else enjoin'd me,
Where I a Prisoner chain'd, scarce freely draw
The air imprison'd also, close and damp,
Unwholesome draught: but here I feel amends,
The breath of Heav'n fresh-blowing, pure and sweet,
With day-spring born; here leave me to respire."*

(Milton, 2000 p 6 from line 1)

This connection between prison and breath is also echoed in the *The Prisoners' Chorus* from Beethoven's *Fidelio* (the prisoners have a rare opportunity of open-air exercise):

*"O welche Lust, in freier Luft
Den Atem leicht zu heben!
Nur hier, nur hier ist Leben;
Der Kerker eine Gruft."*

*(Oh, what pleasure to breathe easily in the free air.
Only here is life; the prison is a tomb.)*

These references use breath to illustrate death, anticipation, freedom and beauty, demonstrating its integral significance, affirming it as an intrinsic part of the human condition. This goes some way to frame understanding of what it is to be breathless and to witness breathlessness, resonating as something felt subliminally, if not always articulated.

Appendix 6 is a poem, written in conjunction with the Life of Breath (McNaughton and Carel, 2015-2020) project by Alexandra Parvan (2020), a Psychology Professor, to portray the experience of breathlessness. This poem conveys the ‘invisibility of breathlessness’ (McNaughton 2017) which cannot be seen, measured or quantified but only be experienced by the person with the condition. The author suggests that poetic inspiration can help others’ breathing, by making visible aspects of the human experience that are not easy to express in a literal usage of language. These aspects are often not even sensed or perceived as being there by those experiencing it themselves. As in all art, what is uncovered is communicated to others with immediacy, and therefore with an efficiency beyond other forms of expression, description, explanation, analysis, or interpretation. Parvan suggests that the use of the arts might help HCPs to see their patients in a way that caring for them is enhanced, bringing comfort and contentment to both (McNaughton, 2020).

Poetry can indeed capture experience more eloquently than literal language. The poem, by Rouf (2020) in Appendix 7, from a collection by people working in the NHS spoke to me about the challenge of adequately recording a clinical encounter. This poem says so much about the experience of the clinician in witnessing the distress of the patient, capturing the inadequacy of the computer recording systems where there has been a deep connection between two human beings. The implication of trying to quantify what has been a profoundly qualitative, intimate human experience adds to the experience of bearing witness to distress

for the clinician. This focus of the poem on experience, brings understanding beyond what was said and done to inform what it feels like to care for another person.

The provision of care to others, from both a medical perspective and lay perspective is written about extensively and gives insight into the human experience beyond its effectiveness or efficiency. Walt Whitman (1819-1892), a poet and nurse volunteer in the American Civil war wrote extensive diaries of his experiences. His understanding of the importance of relationship within care is that it is as vital to recovery as medical management:

“To many of the wounded and sick, especially the youngsters, there is something in personal love, caresses, and the magnetic flood of sympathy and friendship, that does, in its way, more good than all the medicine in the world... Many will think this merely sentimentalism, but I know it is the most solid of facts.”

(Whitman, 1999, p85)

Whitman’s diaries communicate his own personal fulfilment in attending to the soldiers’ needs, as a lay person within the hospital setting. He was able to observe what matters most in caring for patients beyond medical interventions and confidently recognised the value of his engagement with the wounded soldiers. This fulfilment and privilege of care is also captured in Kate Mosse’s book *“An extra pair of Hands”* (2021). Mosse recounts caring for both her parents and mother-in-law, exploring the complexity of this intimate role. While she recounts the challenges and frustrations of caring, she balances the popular narrative of the ‘burden of care’, often referred to in nursing, with a sense of reward and satisfaction recognising the privilege of journeying with a loved one until the end of their life. Mosse acknowledges the invisibility of care in society, that it is a feminist issue and the imperative for it to be prioritised in the political agenda. These points will be explored in more detail in chapter 6 and are recurring features of the care debate.

3.4 How wider understandings have shaped this study

Wider understanding of breathlessness has framed breathing and breathlessness in a context beyond healthcare recognising how it is portrayed as inextricably linked to living, wellbeing and our connection with being in the world. When considering the lived experience of participants (Jellington *et al.* 2016, Bailey *et al.*, 2004 and Tarzian, 2000) they were also in the world, as nurses but primarily as beings shaped by cultural beliefs and expressions of breath and breathing. These will of course have shaped their experience of bearing witness to breathlessness beyond their clinical role, unconcealing the unconscious influences that contributed to their thrownness.

As a hermeneutic phenomenological study, consistent with the methodology, this has framed the study from the outset to span time, discipline, genres and culture. These influences are so often hidden by the “natural attitude” so through their exploration with phenomenological thinking, the reader is provoked to consider these influences on subliminal thinking regarding breath and breathlessness.

This focus on the “phenomenological nod” toward literature, methods, data and analysis have led the study towards unconcealing wider understandings through experience of breath and breathlessness.

3.5 Conclusion

This hermeneutic literature review has sought, with guidance of Smythe and Spence (2012), to provide an account of the literature that has informed my thinking when formulating the research question and the decision making throughout this research project. This began by making explicit my fore-structures of understanding when approaching the literature. With limited understanding of the experience of supporting people with breathlessness documented in the literature, insight from wider research on the ‘experience of nurses providing care’ reveals the challenge of this role. Looking beyond the nursing literature to the

Life of Breath Project (McNaughton and Carel, 2015-2000) and Oxley and Russel's (2020) insights, the life-giving symbolism of breath and breathlessness are explored. Exploration of different cultures, religions and sacred texts enables appreciation of the power of breath. To breathe is to live so an absence of breath equates with vulnerability and the risk of being-toward-death. This is a universal truth across history, cultures and religions that is depicted through the arts. The chapter concludes with two poems (appendix 6 & 7). They show how prose can evocatively convey experience, of utmost relevance for CRNSs bearing witness to the distress of breathlessness. Finally, an account from Walt Whitman's diary highlights the fulfilment of care for a nurse, identified amidst the challenge of caring for wounded soldiers. This sense of fulfilment will be explored in more depth in chapter 6 when the experiences of participants caring for people with breathlessness reveals the complexity of care, alluded to in this chapter.

I now move onto the methodology: outlining my position and decision making when executing this project.

Chapter 4 Methodology Chapter

“Nothing has such power to broaden the mind as
the ability to investigate systematically and truly all
that comes under thy observation in life.”

Marcus Aurelius

4.1 Introduction

The research question asks, ‘what are the experiences of community respiratory nurses in supporting people with breathlessness?’ The primary focus of the research question; experience, has steered the research design to a qualitative study and specifically to hermeneutic phenomenology methodology. This chapter will, following a brief overview of the purpose of the study, examine the chosen paradigms of constructivism and interpretivism to justify the choice of phenomenology and in particular Hermeneutic phenomenology (HP). An outline of HP as a methodology used in nursing research identifies its use to unconceal taken for granted phenomena, confirming it as the methodology of choice in this study to reveal new knowledge from community nurses’ experiences of supporting people with breathlessness. As Heidegger’s philosophy has shaped decision making throughout the study, a brief overview of the Heideggerian notions is referred to in order to give the reader clarity. I also outline the particular influence of Smythe *et al.* (2008) on my decision making for study design and analysis of the data.

As an insider researcher (a practising community respiratory nurse and researcher) I examine my positionality in the study, considering the limitations but also the opportunities this brings. This leads me to explore the importance of reflexivity in an HP study, integral to the rigour of the study. I include brief excerpts from my reflexive diary throughout this

chapter to identify how my thoughts shaped decision making and explore member checking here.

The methods section then outlines the ethics process and then recruitment, identifying the particular challenges of recruiting community respiratory nurses in a Respiratory Pandemic. I describe my data collection by using in-depth interviews with participants, on the online video platforms of Zoom and MS Teams, and explain the process of analysis. After the data was collected, transcribed and pseudonymised, I explain the three stages of analysis of crafting stories, revelations through Heideggerian notions and revelation through attunement. This process reveals the richness of the data and new understandings for nursing. This chapter concludes with a discussion about the methodological and methods challenges.

In order to address the research question, I interviewed twelve CRNSs about their experiences of supporting people with breathlessness. HP informed my analysis, revealing new knowledge from this process. As I have set out in my pre-understandings (Chapter 2), my position as a CRNS and researcher recognises that supporting people with breathlessness is a significant component of care for CRNSs. In order to make my position explicit, decision making from conception through to execution of this project will be examined and justified in order to provide an audit trail and demonstrate rigour.

4.1.1 Excerpt from Reflexive Diary Oct 2020

Why have I chosen this subject of breathlessness? It has arisen out of my own preoccupation following a particular clinical encounter, resulting in a particular interest/investment in the outcomes, a passion even.

The particular focus- nurses' experiences of caring for someone with breathlessness- came about because, as a community respiratory nurse myself, I was immensely impacted by the experience of caring for a particular patient with interstitial lung disease (ILD). I wanted to

take the learning I gained from that situation and understand if this was something that might impact other nurses, and as a consequence their patients.

4.2 Theoretical context of the study

Each practitioner's beliefs and values are shaped by their own theoretical perspective, determining how we view human beings, nursing and health (Stevens, 1984). My own theoretical perspective was influenced by Jean Watsons' theory of human caring (Watson, 1985) but particularly shaped by Parse's theory of Human Becoming (Parse, 1992). Parse's theory is focused on the world of human experience, challenging the medical model in focusing on an individual's personal values and priorities. Parse cites Rogers, Heidegger, Sartre and Merleau-Ponty as inspiration for her theory which offered a unique human science perspective for nursing (Parse, 1997).

Parse's theory guides nurses to focus on quality of life from each person's own perspective as the goal of nursing. It therefore fits well when caring for someone with a life limiting disease like COPD, suffering with refractory breathlessness. Considering care from the person's perspective, their experience and wisdom to make choices in their own health care, shifts power from the nurse to the patient and creates the opportunity for nurses, patients and families to reach profound dimensions of the human experience and holistic nursing care. The influence of phenomenologists on Parse in establishing the theory, the focus on lived experience and holistic care all align with the ontological focus of this project, offering a theoretical context for the project. The research question, focused on the experiences of community respiratory nurses, aligns with the central theme in Parse's theory focused on the world of human experience.

4.3 Research paradigms

Justification of the choice and particular use of research methodology and methods reflects personal assumptions about reality; to explore these assumptions is to ask about theoretical perspective (Crotty, 1996).

Paradigms can be defined as sets of beliefs that provide theoretical frameworks for the purpose and conduct of research (Kuhn, 1962). These beliefs relate to both ontology, that is, the nature of reality or realities, and epistemology, what is known about reality or realities (Corry, Porter and McKenna, 2018). Epistemological assumptions guide research decisions and how access is gained to the reality of the phenomenon in question (Bryman, 2012). Historically nursing research, dominated by the medical model, associated itself with positivism as a guiding paradigm for research (Clark 1998, Corry, Porter and McKenna, 2018). However as different research questions are asked and understanding of other paradigms has grown, methodology has been increasingly selected based on the nature of the research question. Nursing is a complex interplay of art and science and the research methodologies used to explore it should reflect this. The limitations of the positivist concept of truth and inquiry have exposed the reductionist view to deny the importance of subjective, social, spiritual and interpretive aspects of the person and their relationships, centred at the heart of many nursing research questions (Clark, 1998).

The positivist position that all knowledge can be observed, measured and recorded, was rejected by post-positivists who took a different perspective of truth, accepting that a multitude of factors enable us to gain knowledge including lived experience and metaphysical laws (Corry, Porter and McKenna, 2018). Kuhn (1962), one of the fore-founders of post-positivism, identified the complexity and evolving nature of knowledge to conclude we are never in a position to prove the universality of findings. While post-positivism rejects many of the tenets of positivism, it still takes a realist perspective of science and seeks causation, prediction and explanation in the patterns and regularities of life (Corry, Porter and McKenna, 2018).

In recent years Evidence Based Practice, advocated by Sackett *et al.* (1996), has become synonymous with accountable, professional nursing practice. However, as Avis and Freshwater (2006) suggest, the value of scientific evidence has been overemphasised, underplaying the role of clinical judgement and individual nursing expertise. They highlighted

the importance of knowledge-based practice asserting the value of nursing expertise and experience as a fundamental feature of empirical epistemology rather than attributing knowledge...

"to an irreducible or mysterious concept of intuition".

(Avis and Freshwater, 2006, p217)

This is supported by Flaming (2001) who advocated the use of phronesis to guide nursing practice over 'research-based practice'. Phronesis was defined by Aristotle as a "state of grasping the truth, involving reason, concerned with action about what is good or bad for a human being." (Aristotle, trans. 1980, p 154). Applied to nursing practice, it is practical wisdom that is rational and ethical, associated with the right action in a real situation (Maxwell, 2019). Flaming argued that priority in practice is often afforded to research over other ways of knowing that are devalued and deemed inferior. He suggested that if phronesis alone guided nursing practice, "a desire for patients' genuine happiness or human flourishing " would prevail (Flaming, 2012, p251). However, the debate about how to organise methodology between phronetic social science and positivists has moved on somewhat (Flyvbjerg *et al.*, 2012). Rather than a focus on methods that weigh up the benefits of quantitative versus qualitative, priority has shifted to 'problem driven over theory driven research', focusing on real world problems (Schram, 2012). Therefore, as the nature of research questions expand beyond positivist thinking, adopting paradigms and methodologies that address the research question can enable the true complexity of nursing practice to be explored and will progress nursing knowledge. My research question: focused on the experiences of community respiratory nurses, assumes a relativist perspective that meaning exists in multiple experiences, these experiences may conflict, but they are the true perceptions of the participants (Bryman, 2012). These experiences are influenced by context and, consequently, meaning may change over time. My interest was not simply to focus on the specific clinical condition of breathlessness or the professional task of implementing care, which might have been realist in nature describing a single reality but to explore the

experience of providing care. My research question is framed to seek the experiences of community respiratory nurses, so it is appropriate to use an epistemological approach that acknowledges truth and reality are subjective. Therefore, I reject positivism moving away from the Cartesian duality of reality being 'out there' and separate from the individual (Koch, 1998). The two principal paradigms that acknowledge this relativist perspective are constructivism and interpretivism which will now be explored.

4.3.1 Constructivism and Interpretivism

Interpretivist research gives precedence to subjective views and experience, acknowledging there are as many different perceptions in the world as there are individuals perceiving and experiencing the world. Husserl (1859-1938) suggested that to ensure rigour, researchers should remove themselves from these perceptions to transcend and objectify them in order to reach an understanding, making the researchers interpretations independent of the experiences of the study participants. However, according to Heidegger (1962) and Gadamer (1975), interpretation is not simply a methodological option but the very condition of human inquiry itself, accepting the hermeneutic character of existence (Schwandt, 1998). The Interpretivist position rejects operationism and notions of theory, focusing on the intersubjectivity and means by which the inquirer arrives at the interpretation of human action to seek understanding (Schwandt, 1998). Therefore, the epistemology of interpretivism is that humans construct knowledge as they interpret their experiences of and in the world. The ontological position is relativism, the view that reality is subjective and differs from person to person on social and experiential levels (Guba and Lincoln, 1994).

Constructivist research is also concerned with experience as it is lived but focuses on a belief that individuals construct knowledge, truth and reality in order to make sense of their experience. As the individual undergoes new experiences, these constructions are constantly modified and adapted (Schwandt, 1998). Guba and Lincoln (1989) identify that in constructivism, the observer cannot be disentangled from the observed in their enquiry, so

“the act of inquiry unfolds through a dialectic of iteration, analysis, critique, reiteration, reanalysis, and so eventually leads to a joint (among inquirer and respondents) construction of a case i.e., findings or outcome”

(Schwandt 1998, p243).

Therefore, unlike interpretivist philosophy that suggests there are multiple perceptions of the same world, the constructivist philosophy maintains there are multiple constructions, or multiple realities. So, the epistemology of constructivism is the mind is active in the construction of knowledge, seeking to measure, make sense of and give meaning to the natural world. Ontologically, constructivism takes a relativist perspective, that there are multiple truths as a result of social processes that are context bound (Fish, 1989). I have my own experience of the research question and take an emic perspective (Holloway and Galvin, 2017) seeking to uncover meaning from the participants' experiences, co-constructing knowledge. This blurring of boundaries makes articulating a distinct chosen paradigm challenging (Kelly *et al.*, 2018a). This is reflected in the execution of my research project by co-construction with the participants and myself gathering data through in-depth interviews then taking an interpretive approach to the analysis. As a result of establishing these realities rather than perceptions, my interpretation as a researcher is transactional: researchers and participants are co-constructors of knowledge reliant on the participants' views and experiences (Denzin and Lincoln, 2000). But as Guba and Lincoln (1989) argued, constructivism and interpretivism are similar notions at the heart of the everyday world of lived experience and to disentangle them is a somewhat artificial exercise (Schwandt, 1998). Hermeneutics (interpretation) and verstehen (understanding) have been the main influences on the development of Interpretivism (Kelly *et al.*, 2018a) yet Kuhns' (1962) assertion that constructing meaning from experience is how individuals make sense of their world suggests an intertwining with constructivism (Crotty 1998) and makes the distinction of paradigms less clear cut.

4.4 Choosing a research methodology

Methodological choice begins with the research question and the aims of the study. The focus of my question is 'lived experience' and aligns with interpretivist/constructivist paradigms that there are multiple truths and realities. There are a number of research methodologies that sit within these paradigms. These include ethnography, case study, narrative inquiry and phenomenology. The rationale for my chosen methodology returned me to the focus of the question; I do not wish to capture the culture of an organisation (ethnography) (Topping, 2015) because I am interested in the lived experience of the individual. However, if there had been no constraints on time or resources, the opportunity to study the participants 'in the field' could have enhanced data collected, crystallising the observations, the interviews and demographic details of participants. This was not a possibility at the time the study was undertaken, and capturing participants' accounts of their experiences was the focus of the study, so ethnography was not used. I do not wish to directly link the participant with the phenomena (case study), as this would analyse the phenomenon to generate a hypothesis (Topping, 2015). Whilst this puts the focus on the phenomenon of supporting people with breathlessness, the outcome is to create a hypothesis: an ontic rather than ontological outcome. My research question seeks to reveal what it is like to experience that phenomenon; choosing phenomenology puts a focus on individual participants' views, experiences, feelings and expectations as central rather than trying to fix or predefine it (Smith *et al.*, 2009). For this reason, phenomenology is the methodology of choice.

Phenomenology is both a philosophy and research methodology. The central component of the philosophy deals with the problem of appearance and human perception (Sokolowski, 2000). This is depicted by Plato's allegory of the cave in which Plato claimed that knowledge gained through the senses is no more than opinion, that to have real knowledge we must gain it through philosophical reasoning (Sokolowski, 2000). Phenomenology as a

methodology is used to examine pre-reflective, subjective human experience as it is lived prior to its theorization by science (Carel, 2016). It seeks understanding rather than explanation, offering

“the possibility of plausible insights that bring us in more direct contact with the world”

(van Manen, 1997, p9).

The nature of understanding underpins Heidegger's ontology, he presents human understanding through being in the world, where we are always interpreting in order to understand. An explanation is usually constructed to describe a set of facts, aiming to clarify the causes, context and consequences of those facts, therefore seeking explanation is to take an ontic position.

Phenomenology can be approached descriptively, following the philosophy of Husserl (1859-1938), interpretively (hermeneutically) following Heidegger (1889-1976) or through Interpretive Phenomenological Analysis (IPA). These schools of phenomenology will be discussed and evaluated regarding their fit with the research question and, for both descriptive and IPA, justification for rejection is outlined. Rationale for the hermeneutic phenomenology as the chosen methodology is presented and discussed, introducing the philosophy of the methodology.

Phenomenology was first presented by Edmund Husserl in the mid nineteenth century. Descriptive phenomenology was described by Husserl; he was concerned by the effect of consciousness and subjectivity when researching phenomena. He believed that experiential epistemology, that is, knowing through experience, was the primary focus of inquiry. In order to achieve scientific rigour, he believed intentionality removed the person from the world of the phenomena to allow understanding of the phenomena. Husserl took a positivist, reductionist view that aimed to eliminate the researchers own perceptions from the phenomena to reveal the essence of the phenomenon from objective data. This reduction

involved 2 stages. The first, eidetic reduction uses epoche (setting aside assumptions and beliefs) “bracketing-out” presuppositions, that strips away the researcher’s preconceptions of the phenomena to “experience its pure essence” (Converse, 2012, p29). The term bracketing, a mathematical metaphor, reflected Husserl's early work using mathematics and psychology and his ideal of achieving rigorous scientific outcomes despite his disillusionment with positivism (Cohen, 1987). Husserl’s intention for bracketing was to achieve the second stage of reduction; a “naïve, natural, objective attitude to the world” (Holloway and Galvin, 2017, p 222) by temporarily suspending what we think we already know. This phenomenological reduction freed the phenomena from all trans-phenomena elements (Cohen, 1987). Hamill and Sinclair (2010) suggested bracketing enabled the truth to be *“arrived at based on the participants’ descriptions rather than the sole interpretations of the researchers”*

(Hamill and Sinclair, 2010, p23).

Any research will have limitations and the intention of bracketing is to enable a clear audit trail for the reader to follow, demonstrating greater transparency and rigour in research (Holloway and Galvin, 2017) through reduction. Descriptive Phenomenology seeks to address epistemological questions by using the data to delineate the structure of the phenomenon. Examples of such questions are What is dwelling-mobility for older adults? (Galvin and Todres, 2010) and The Enigmatic phenomenon of loneliness (Dahlberg 2007). These studies aim to draw eidetic knowledge of the phenomenon through description. The whole and the parts of the phenomenon are considered. In this way the phenomenon is described but empirical variations and ramifications are discussed which do not go beyond the data. My question addresses the experience, therefore an ontological perspective of supporting patients with breathlessness and focuses on the lived experience of the nurse being in that situation. If a Descriptive Phenomenological approach was adopted this would focus on the structure of the phenomenon, all presuppositions bracketed out to give pure

description of the phenomenon. Using this approach would result in focusing on describing the essential features of supporting patients with breathlessness in a reductive fashion, perhaps considering cause, physical features and components of supporting people, not moving beyond the data. This feels to be a neutral, passive and somewhat disinterested act. The aim of this study is to explore the experiences of participants and as well as describe these experiences, to reveal new understanding from the data analysis. For this reason, I have rejected Descriptive phenomenology.

Interpretive Phenomenological Analysis (IPA), framed as a phenomenological research methodology to make sense of the experiences explored, was developed from research in psychology. Relatively small (less than 10), homogenous samples are used to examine convergence and divergence in some detail (Smith *et al.*, 2009). Data collection is in the form of semi-structured interviews. Transcripts of interviews are analysed line by line, case by case through systematic qualitative analysis creating a narrative account where the researcher uses analytic interpretation, supported with verbatim extracts from participants. This microlevel analysis of the participants' accounts, looking for themes, is appealing to some novice researchers because the process of analysis is clear and concise, giving detailed procedural guidance (Brocki and Wearden, 2006). However, van Manen (2018) challenges the psychological methods used by IPA, questioning their fit with Phenomenology. Whilst phenomenology might be difficult to grasp

“... it should be possible to see that it differs radically from psychological or personal sense making of a person's own experience.”

(van Manen, 2018, p 1960)

IPA feels too reductive for this research question, focusing on the verbatim narrative rather than the whole story being told; temptingly straightforward but diverging from the goals of phenomenology described by Heidegger. For this reason, I have rejected IPA.

The reductive approach of descriptive phenomenology was challenged and rejected by Heidegger, a student of Husserl. He focused on the ontological question of being in the world of the phenomenon rather than on the phenomenon itself. Heidegger's concept of *dasein* "being-in-the-world", suggests an openness which is an affective, situated and embodied experience (Holloway and Galvin, 2017). Heidegger took a primarily ontological approach, attending to the process of understanding (Koch, 1998). This position was supported by Sartre (1905-1980) who is famously quoted as saying "existence precedes essence", it is the understanding of consciousness that is directed towards being. Heidegger accepted that being in the world is about temporality, so rather than suspending suppositions, researchers examine them and make them explicit (Holloway and Galvin, 2017). The rejection of "bracketing out" the researcher's presuppositions in interpretivist phenomenology does not mean the researcher's position is not recognised. Heidegger's (1995) notion that we always approach phenomena with fore-having (already there knowing), fore-sight (the ability to imagine how it might be) and fore-conception (the ideas we bring) acknowledged the importance of the researcher's position (Smythe, 2011). This approach has been reflected in the present study where my pre-understandings are outlined in Chapter 2 to demonstrate my position when approaching this research. Finlay (2008) recognised that if we are to understand, we must recognise what has influenced our world view to recognise our influences and biases, and through this acknowledgement we can be open to other people's meanings. This is supported by Flood (2010) and Tuohy *et al.* (2013) who suggested the aim of interpretive phenomenology is to have the awareness of how these factors will influence how we understand and interpret data. This is especially important in nursing where context shaping lived experience will provide a deeper understanding of the phenomenon being studied (see Johnson, 2000).

The philosophy of phenomenology, in understanding the world that we are situated in, is central in Hermeneutic Phenomenology as a methodology. Lived experiences are the "data of phenomenological research" (van Manen, 2017 p 814). Lived experience does not have

anything to do with phenomenological method, it is just the name given to life experience as it is lived every day. Heidegger argues that everyday experiences inevitably fade in meaningfulness as we live our lives and are therefore concealed, hidden or faded in meaningfulness to taken for grantedness. If this was not the case, we would not need phenomenology. The challenge for phenomenology is to recover the lived meanings without objectifying these meanings and turning them into positivistic themes and sanitised concepts (van Manen, 2017). Phenomenological inquiry enables implied meanings to become explicit, to be seen and heard and reflected upon. In order to understand a phenomenon fully, it is necessary to access it through the subjective lens of the people experiencing it to reveal and understand the multi-layered world of reality.

4.4.2 Rationale for the choice of Hermeneutic Phenomenology (HP)

Interpretive phenomenological inquiry seeks to address ontological questions focused on an experience and being in the world, therefore meaning is attributed to the phenomenon. It seeks to stay close to the ontologic (the experience itself) rather than trying to articulate a more generalised analysis of essence (ontic) (Smythe *et al.*, 2007). Examples of this include Taylor's (2014) examination of sexuality and intimacy in terminal illness and Suddick *et al.*'s (2020) exploration of the experience of stroke survivors on an acute stroke unit. These studies look to go beyond description to the meanings attributed to those experiences through phenomenological interpretation. HP allows a greater heuristic and relational approach generating a greater understanding of the experience. In much health care practice, meaning is often tacit; taken for granted and hidden from sight, this can be because the taken for granted ways of doing things cover over the phenomenon (Smythe and Spence, 2020). This seems the case especially in Respiratory Nursing literature, where there is very little research exploring the experience of being a specialist nurse. Research

focuses on the functional role of the nurse (Kelly *et al.*, 2018b) so that assumption fills the gap with no insight into the lived experience of this role.

Hermeneutic phenomenology is the methodology of choice to address this research question because it is synonymous with being in the world of the CRNS. Heidegger (1962) argues that in order to fully understand this position “only as phenomenology is ontology possible” (p60), suggesting that only through phenomenology the nature of being can be explored. Hermeneutic phenomenology is synonymous with being part of the world (Heidegger 1962, Gadamer, 1976). I come to my position of researcher as a practising community respiratory nurse. In the world of my research participants, a Heideggerian approach recognises that meaning is influenced by my own perspective of the subject, framing the project design from the questions asked to the interpretations made (Rodriguez and Smith, 2018). This context is important at every step in the research process due to my prior knowledge, learning and own experience of supporting people managing their breathlessness in clinical practice. My emic approach influenced both my understanding and interpretation of the data, resulting in co-constitutionality, which refers to a blend of participant and researcher meaning (Bryman, 2012). If I had had to bracket-out my presuppositions using Descriptive Phenomenology, I feel this would have limited the authenticity of the study, eliminating my experience as a respiratory nurse and what this will bring to the study. Smythe *et al.* (2008) recognise that to research in a Heideggerian hermeneutical manner is to recognise that phronesis is the predominant mode of being. This aligns with Maxwell’s (2019) commentary of the philosophical underpinnings of Professional doctoral research identifying that phronesis is

“practical wisdom [that is] rational and ethical, associated with the right action in real situations “

(Maxwell, 2019, p8).

Heideggerian phenomenological methodology fits not only with my own philosophical values but those inherent in professional doctorate research. This was achieved in this research

project by embedding Heidegger's philosophy through every stage of the research process. It is this philosophical underpinning that enabled the phenomenological leap from description of lived experience to interpretation and co-construction of new knowledge.

4.4.3 A brief synopsis of Heidegger's philosophy and notions

Hermeneutic phenomenological interpretation is a methodology that is informed by the philosophy of Heidegger and Gadamer to guide methodological theory and interpretive decision making (Johnson, 2000). Lived experiences are explored through a phenomenological lens to reveal and extend understanding of the phenomenon using interpretation and understanding guided by Heidegger. In order to present what was, at the time, a very different approach to knowledge and truth, Heidegger created new words deliberately so that the reader would seek clarity and meaning of his philosophy rather than inferring existing meaning. For this reason, the terms or Heideggerian notions need to be clarified. I will therefore present a brief explanation of Heidegger's philosophical thinking in order to guide the reader through Heidegger's key notions referred to in this study.

Heidegger believed our understanding of being in the world has been covered up by day to day (ontic) common patterns of being in the world. Awareness of our being-in-the-world, always making interpretations to make sense of things is unconscious and is called the *natural attitude*. This is thinking that is subliminal, unchallenged and generally functional. A *phenomenological attitude* departs from this to question the way we experience the world of the phenomenon to give a deeper level of interpretation, informed by the philosophical tenets, existentials and modes of being-in-the-world outlined to draw out what is already known but hidden. Through this phenomenological attitude, the hermeneutic circle and 'fusion of ideas,' meaning can be unconcealed and unfolded (Suddick *et al.*, 2020). 'Fusion

of ideas' is a concept developed by Gadamer (2008) that describes the awareness of how thinking between oneself and 'the Other' can be done. From this Gadamer introduces the idea of prejudice, suggesting that rather than being seen as negative, it is a means of acknowledging and opening ourselves to the detail of our connectedness and our pre-understanding. The other's idea "addresses us" (Gadamer, 2008) moving us forward in our hermeneutic thinking. In this way, moving back and forth in the hermeneutic work within the circle, dialogue with the data and the process of interpretation offers a gateway to "*extend meaning from what is directly given*" (Gadamer 2008, p536) to discover a new perspective and shared understanding of the phenomenon.

Heidegger's unique way of understanding human experience begins with *dasein* (being-in-the-world). Heidegger stated

"so when we designate this entity with the term 'dasein' we are expressing not its 'what' (as if it were a table, house or tree) but its' Being."

(1962, p42)

Being in this sense is not about the functional aspects of being, it is something entirely ontological, seeking meaning and understanding in the experience we are engaged in, like being-in-love. This is the way human beings understand themselves and their relationship to the world (Dibley *et al.*, 2020), making decisions and understanding phenomena through their lived experience of the world. Context for Heidegger is central to being, so *dasein* is impacted by historicity and temporality that situate us in the world. This interrelationship of all things from the time in history we were born, our class, race, gender, geographical location in the world as well the unfolding of circumstance of time (rather than the traditional chronological order of time) informs the possibility of *dasein*. It is only through *dasein*, we can begin to understand others when we appreciate the importance of who we are and how we exist in our own lifeworld (Heidegger, 1995). For the participants in the study their *dasein* is embodied in being-a-nurse. Their practical "know how", beliefs and values have become

intrinsic to them as individuals through their personal and professional experiences.

Exploring Dasein uncovers what lies beneath their everyday practices and interactions in their lifeworld's to give new perspectives and insights; understanding is deeply informed by experience. Heidegger is clear that in being-in-the-world in Dasein, we are being-toward-death. This is a universal truth that Heidegger refers to as authenticity.

Heidegger's view of *authenticity* moves beyond traditional thinking of the term. While authenticity is to be true to one's own self and to be one's own person, authentic dasein looks towards one's own death and back to its birth, and beyond its birth to the historical past (Inwood, 1997). To Heidegger, living authentically is to seek our "own most potential to Being " (1962 p312) grounding ourselves in the world without taken for granted assumptions that is entirely experiential (Dibley *et al.*, 2020). Heidegger recognised that in reality, most of us are unable to operate in this way in everyday existence and we live inauthentically because we conform to '*the they*' or '*das Man*'. For Heidegger this is 'others' or the norm of society, so we opt to do what is culturally acceptable, what is expected and is handed to us, and are limited by conscious boundaries. This is a decision, and we can choose to engage authentically with meaningful existence in our personal lives but is more challenging professionally. For nurses, including the participants in the study, living and working authentically in Heidegger's meaning would be to focus on their own death and dying, deflecting away from patient care to themselves. Professional guidance requires *fallenness* into the nursing role, arguably conforming to '*the They*' and being inauthentic in order to fulfil the required role of the nurse to care for and focus on others. However, in exploring the lived experience of caring for their patients with breathlessness, participants revealed both personal and professional impact of witnessing distress, especially at the death of a patient.

Being-toward-death is an aspect of authenticity and of fundamental ontology. As Heidegger explained, dying is a phenomenon that needs to be understood existentially (1962).

“Only when dasein has grasped the finitude of its existence can it be brought back from the infinite multiplicity of its possible ends to the simplicity of its fate”

(Heidegger, 1962, p384).

Being-toward-death, as part of Dasein's Being, is evident in everydayness. However, in everydayness, one's own most being-toward-death is covered up with inauthenticity, falling into the 'they' world, pushing ahead with everydayness through denial and repression (Gullick and West, 2020). For many people living with a life limiting illness, this inauthentic positioning enables them to stay in the concerns of the everyday. The experience of breathlessness as part of chronic respiratory disease puts the possibility of death for patients and families in their consciousness (Pascal *et al.*, 2016). In authentic positioning of being-toward-death that is so often covered over and put off by the activities of everydayness, dasein faces the possibility of one's own death that could happen at any time. Accepting one's own death as certainty can lead to angst, a disintegration of self, for some a fear of nihilism and a fear of vanishing ontologically (Gullick and West, 2020). Yet dasein comes to understand that giving oneself up to death as the greatest possibility of its existence and frees itself from this acceptance of death, rather than be lost in 'the they' world of inauthenticity, dasein can authentically appreciate and choose the possibilities ahead (Gullick and West, 2020). When dasein understands its finitude, it can no longer take things lightly or rest comfortably but is brought to the “simplicity of its fate” (Heidegger, 1962, p384). For nurses caring for patients who are toward-death, the challenge is personal as well as professional. Seno, (2010) described all the nurses in her study as taking an authentic attitude to death. While they were clearly comfortable with death as part of their clinical responsibilities, true authenticity facing our own finitude is a call to consciousness. For these nurses to bring themselves to the clinical encounter at the time of their patient's death would most likely be an inauthentic encounter, because they would be thinking about what they

were doing for the patient rather than their own being. Heidegger suggested facing death with another person one needs to be an 'extraordinary other' because of the way we culturally deny death (Heidegger, 1962). Haraldsdottir's (2011) study based in a Scottish hospice explored Heidegger's concept of being-with as a moment of engagement between nurse and patient regarding death and dying. Haraldsdottir (2011) identified the nursing staff had adapted being-with to provide comfort in order to protect themselves from engaging with painful emotions associated with facing death. As discussed previously, in creating an upbeat, cheerful environment for patients, only enabling time to 'be-with' their patients through task orientated care; they created the notion of 'death not yet'. This study demonstrated that the hospice nursing staff were no different to the general public in the way they dealt with death and dying, acknowledging that engaging with death is painful. It challenges the notion that by working in the hospice, nurses will adopt the values system built on hospice philosophy (McNamara *et al.*, 1995). This study resonated with my own experience in clinical practice and my study findings. It suggested that nurses, like others, are shaped by their own experiences and values that contribute to our thrownness.

Heidegger recognised that we are *thrown* into life situations that can shape our existence, a central feature of *dasein*. By thrown, Heidegger does not mean we are thrown by situations, rather we are thrown into situations. This is our starting point and where we find ourselves. This has been touched upon regarding historicity and temporality but relates specifically to taken for granted situatedness in our environments. Our 'thrown' behaviour may be unconscious and automatic (Dibley *et al.*, 2020) influenced by preconceptions, cultural and temporal existence of what has gone before. A human life is never neutral or undetermined but always has some definite content already (Withy, 2011). Our thrownness highlights our finitude in the limitations of our understanding of ourselves beyond what we know (Withy 2011). But *thrownness* also suggests looking forward and future possibilities, *dasein* is always present within this. The presence of thrownness is disclosed through attunement.

Attunement (Befindlichkeit), or mood (*stimmung*) implies our sense of 'being', it creates a tone and is always present- we are always attuned to mood. This is one of the most frequently misunderstood concepts in Heidegger's work yet one of the most important (Gendlin, 1978). *Befindlichkeit* refers to ontology in the sense human beings are, that aspect of being that makes them have moods or feelings. There is no meaningful direct translation into English but "*sich befinden*" (finding oneself) is the closest and relates to situatedness. This refers to how you feel, how things are going for you and what sort of situation you find yourself in. Gendlin (1978) referred to this new noun coined by Heidegger as "how-are-you-ness" or perhaps "self-finding" (p2). "The mood has already disclosed, in every case, being in the world as a whole, and makes it possible first of all to direct oneself toward something" (Heidegger 1962, p176). In other words, mood is presupposed by intentionally directed thoughts and experiences. For example, in order to find something threatening, one must be open to the possibility of threat. There will always be an openness to certain kinds of possibilities and not others. Attunement is not conscious and is only uncovered at times of breakdown (Heidegger, 1962). Crowther *et al.* (2012) considered attunement at birth, they described the thrownness and mood of the mothers in their birth stories. They reveal a new understanding of joy at birth that can be easily disrupted in the possibility of something going wrong. This study revealed that an understanding of attunement that might be a primordial, prereflective entity, can help to reveal the experience and unconceal the phenomenon of interest. Attunement has played an important role in this study. The mood of each interview was explored and when considered collectively, a new understanding of the phenomena of interest was revealed (explored in the analysis and discussion in chapters 5 and 6).

A prominent aspect of *dasein* in this study is that of care or *Solicitude*. Solicitude has two senses: firstly, *sorge* which is caring, worrying about something and secondly *fursorge* which

is solicitous care or “caring for ” other people. Care involves both these senses, but its meaning is more fundamental than either (Inwood, 1997). Because of dasein’s being-in-the - world, it has concern for things (*besorgen*) and its solicitude (*fursorgen*) for other people. Although care embodies dasein, it is complex so for the purpose of this study solicitude will be explored through Heidegger’s modes of being of leaping-in and leaping-ahead.

Leaping in is a dominating, inauthentic solicitude which immediately relieves the other of care and in its concern puts itself in the other’s place, leaping in for him. *Leaping ahead* is releasing, authentic solicitude that attentively leaps ahead of the other in order from there to give back care. Authenticity favours leaping ahead, helping others to stand on their own two feet, reducing dependency on them. Although excellence in nursing care is considered to involve the ‘leaping ahead’ mode of solicitude (Draucker, 1999), there are acute situations in nursing care when ‘leaping in’ is called for (such as in the Emergency Department, on Intensive Care or some acute situations in the community) in order to save lives. Esther in Interview 5 is familiar with ‘do-treat-do’ of acute nursing, used to leaping in where care is required. She shares her personal challenge as a CRNS when her patient does not take her advice, requiring her to leap ahead to support him proactively, facilitating independence and self-management. A barrier to leaping-ahead that can distract from the importance of the nurse-patient relationship is technology, arguably less of an issue in the community but the provision of equipment is a focus for CRNSs, nonetheless.

Heidegger warns of the rise of technology, threatening to objectify being and overtake human life. Heidegger suggests it is not technology and advancement that are the threat per se, but how we approach them. When we solely focus on the promise of technology (what it can do) and its enframing of the body, we are separated from other modes of revealing and other facets become concealed and unknown (Zitzelsberger 2004). This is increasingly

evident in health care where *machination* (a term used by Heidegger to describe the essence of technology) can lead to the abandonment of being (Thomson 2011). For nurses, technology is increasingly and uncritically used to provide knowledge of and care for patients (Zitzelsberger 2004) so that nursing work can be task focused and removed from patient engagement. If technology is chosen over other modes of being-in-the-world and is the exclusive view through which the world and truth is unconcealed, we risk being removed from other modes, sacrificing and abandoning Being. Being becomes concealed and hidden. When asked about the challenge of supporting people with breathlessness Belinda, in Interview 2 focused on her provision of equipment (profiling bed and high flow oxygen). This is tangible intervention that was more easily described than her own feelings about her engagement and connection with the patient. The example of Belinda, choosing to share what she did practically rather than how she felt existentially echoes Heidegger's position of how we are in the world.

The state of the uncanny, translated from the German '*unheimlich*' also means not-being-at-home and unsettled. The etymological root of the German word *heim* (home) conveys something familiar and intimate, of running smoothly and feeling secure, not considered until times of disruption (Aho, 2020). Our taken-for-granted familiarity with our lives means we can generally make sense of things, attuned to being in the world in a homelike mood. But the pandemic disrupted this, leaving us anxious and not-at-home. This mood takes away *dasein's* possibility of understanding itself because we are unable to perform ordinary tasks. Yet Heidegger suggested that through our 'fallenness' into the world by being absorbed and distracted by the 'they' entrenched in the world, we are pulled away from what really matters in the belief that we are at home. The frailty of being human and of being-toward-death opens us up to possibilities and concealed meanings. For Heidegger the experience of the uncanny gives us an opportunity for transformation.

As Heidegger's philosophy is deeply rooted in the ontological; it resonates with the philosophy of nursing.

4.5 The philosophy of Nursing and HP in Nursing

The philosophy underpinning nursing aligns with Heidegger in the desire to be authentic, to interact with others and to seek ontological understanding (Haggerty and Grace, 2008).

Understanding the complexity of nursing skills as a combination of explicit and tacit knowledge (Polanyi, 1962) has been challenging with the professions desire to align with the Biomedical model where empirical knowledge is prioritised (Zander, 2007). Carper's (1978) work describing "The Ways of Knowing" in Nursing (Empirics, aesthetics, personal knowledge and ethics) highlighted the complexity and multi-faceted nature of the role.

Carper's work challenged Patricia Benner (1984) to explore other ways of knowing in her publication "Novice to Expert". Benner's work sought to expose what remains unnoticed and taken for granted by identifying and describing nursing knowledge that is embedded within nursing practice to articulate the everyday skills, habits and practices of nurses (Benner and Wrubel, 1989). Benner has contributed to nursing by articulating and making explicit some of these taken for granted practices by observing those involved in an activity, what they are doing and narratives about the situations they are involved in (Johnson, 2000). However, this work has been criticised by Crotty (1997) and Paley (1998) who consider this interpretation of Heidegger's work is incorrect but as Johnson (2000) suggests, her work is perhaps just rather narrow and can be expanded to a greater depth to investigate the meaning of individuals' experiences within the context of their lives. For Heidegger, it is the involvement in the practical world of experience: *dasein* or being-in-the-world that is not a spatial relation but part of an interconnected world of human investment and interest (Johnson, 2000).

Being-in-the-world as temporality reminds us that all our experiences and understandings relate to our own context of culture and traditions. This applies to both participants and the researcher. This then follows that my own research question is grounded in the fore-having, foresight and fore-conception of the research (Gadamer, 1975, Heidegger, 1962), bringing my own context to and embedded within the research. This brings the ontological position to the research question, deepening understanding beyond the ontic position of observing the activity of caring for people with breathlessness, and developing Benner's position when engaging HP. This development of thinking in HP has progressed nursing research to bring a depth of thinking and exploration to many published studies. Phenomenological research methodologies have become increasingly popular in nursing over recent years (Stayt, 2007, Galvin and Todres, 2010, Dibley *et al.*, 2014, Taylor, 2014) demonstrating the importance of progressing epistemological questions to an ontological understanding of nursing practice.

4.5.1 Benner's Novice to Expert

Benner's application of Dreyfus's model of skill acquisition to nursing practice is the framework for her seminal work 'From Novice to Expert'. This model, borne out of understanding the work of chess players and aeroplane pilots places the nurse as novice, advanced beginner, competent, proficient and expert. Each stage is judged by building demonstrable skills in practice.

Benner gives an exemplar in which a clinical nurse, working in an acute medical environment manages the complex care of a deteriorating gentleman. In the scenario, the interventions are clear and measurable, comparable to the role of a chess player or a pilot and demonstrating the nurse's proficiency and expertise. This exemplar demonstrates one of many nursing roles and could not be applied in this, arguably simplistic way, to that of a CRNS caring for someone with refractory breathlessness. The skills required in this alternate scenario are perhaps more tacit and hidden involving advanced communication skills, empathy, as well as in depth knowledge and lived experience of such situations. As Heidegger's notions have demonstrated, each nurse brings their own perspective so their

Dasein, their thrownness and solicitude shape each clinical encounter. While I do believe Novice to Expert remains a useful concept in clinical practice, I do not believe it is applicable to all clinical situations, taking a task oriented perspective to the complexity of care that cannot always be quantified.

4.5.2 Outline of chosen methodology

My chosen methodology is based on the work from Smythe *et al.* (2008), Diekelman and Ironside (2011), Crowther and Thompson (2022) and others. These nurses and midwives have used hermeneutic phenomenology in a range of published studies to bring a rich understanding of the subjects they explore. Hermeneutic phenomenology is argued by researchers to break through the theories of how practice ought to be, to reveal how practice is in lived experience (Smythe and Spence, 2020). They advocate crafting stories (Crowther *et al.*, 2016) from interviews to distil the essence of the story told by the participant from the data as a whole, focusing on the experience rather than the text. Crafting stories could be construed as an abuse of power because the researchers' perspectives are privileged. These concerns are acknowledged by Crowther *et al.* (2016) who suggest that all researchers exert power over participants' data regardless of methodology. Articulation of pre-understandings in this HP study brings openness to the impact of my already there prejudices (Gadamer, 1975).

From crafting stories and remaining within the hermeneutic circle, Smythe *et al.* (2008) describe moving between the data and underpinning phenomenological philosophy to make the phenomenological leap of interpretation, revealing the phenomenon through the story. This is not a straightforward, linear process. The spirit of phenomenology is a process of reading-writing-reading-thinking on a journey until insights “come”. As Smythe *et al.* (2008) suggest

“It is not a process of “do whatever you like” but rather a very attentive attunement to “thinking” and listening to how the text speaks’ ’

(p1389).

This thinking is described as a “phenomenological attitude” (Dibley *et al.*, 2020), suspending the “natural attitude” where we are so familiar with what we see, how we see things and what it is to “be”, that we cannot distinguish from our own view and our judgement is clouded. Thinking with a phenomenological attitude underpins this whole research project from inception, design and undertaking allowing openness and new understanding. Understanding is never complete, when insights are revealed, other aspects are concealed (Smythe *et al.*, 2008) Interviews were not “conducted” (which indicates rigidity and control), they were unique interplays between researcher and participant, as the researcher I am present as a whole being, considering the context and spirit of the interview (Gadamer, 1975). Transcripts were not thematized which puts labels on the experience reducing it to theorise the experience to a generalised nature, instead in thinking in a hermeneutic phenomenological way considered the participants experience and their situatedness, capturing complexity, comfortable with ambiguity (Smythe and Spence, 2020). Data analysis did not reduce, categorise and synthesise; Heidegger believed our understanding is already there and to remove it from its background is to remove meaning and understanding of how it is lived. Therefore, analysis was focused on allowing thinking to evoke meaning and find its own way to new understanding. This came from being fully immersed in the stories and embodiment in enough relevant philosophical notions to see a connection (Smythe and Spence, 2020), trusting the process of interpretation of another’s experiences, revealing hidden meaning. This is by no means easy, it cannot be easily taught or read but has to be lived in a way as to be open to possibility, of still arriving and new possibility that can change us as individuals and health care professionals (in chapter 7 I discuss how this process has changed me). This multi-faceted, dynamic way of being aligns with nursing theory and therefore practice. Watson’s theory of Human Caring (1985,1989) constructed

nursing as a moral idea, a humanistic idea with the central notion of caring (Pearson, Vaughan and Fitzgerald, 2005). This relational approach to practise put authentic presence, existential wholeness, “being” the caring, healing environment and practice of loving kindness and equanimity as the core principles for practice. This alignment to clinical practice and awareness that it can be an ambiguous and evolving process makes HP well placed for nurse researchers, already appreciative of ambiguity from clinical practice. As a researcher exploring my own clinical area, my position as an insider researcher presents opportunities and challenges.

4.5.3 Insider research

Insider research is an ethnographic term. It describes the position of the researcher who also could be a participant in the research, a position that has been debated and scrutinised in the literature (Johnston *et al.*, 2017). As a Community Respiratory Nurse, I have my own lived experience of supporting people with breathlessness. The insider-researcher position is explored by Johnston *et al.* (2017) who suggested the position of nurse as researcher can contribute to the data collected as the experience of the phenomenon is individualised to each person, which includes the researcher. As an insider I share identity, language and a common professional base which did help rapport with participants. Simmons (2007) identified that a drawback of insider research can be that trust can be breached if poor practice is disclosed, suggesting that an assumption is made that as a researcher, I know all about the particular phenomenon in question. Being reflexive and mindful to capture the experiences of others, I actively sought to focus on their experiences rather than mine. This positionality is further challenged by Asselin (2003), warning of the potential role confusion insider research can bring. Asselin suggested that a response to events or analysis from the perspective other than that of a researcher (i.e. a nurse) can result in inappropriate responses or interpretations, overlooking critical observations, premature conclusions and over participation. I recognise the potential for Asselin’s points in my own experience of

research in being close to the subject and the experience being explored. There is a risk of assuming I knew what the participants alluded to when they described a clinical encounter and moved on, rather than seek to clarify their comments and explore in more detail. However, I would suggest this arose more from being a novice researcher than an insider (limitations of the project are discussed in chapter 7). This criticism of the nurse as researcher is challenged by Leslie and McAllister (2002) who identify the skills nurses can bring from their own discipline to gain access to participants and their data. In exploring this issue as “nursedness”, Leslie and McAllister (2002) concluded the role of nurse as researcher can offer deeper understanding of complex health experiences. Nurses can see their world in a new and enlightened way (Crotty, 1998). Patton (2015) suggested heuristic inquiry (making meaning of the nature of human experience: Moustakas, 1990) requires the researcher to have a personal experience with an intense interest in the phenomenon under study, asking the foundational question: *what is my experience of the phenomenon and the essential experience of others who also experience this phenomenon intensely?* The premise of Professional Doctorate research is that the subject comes from clinical practice and is researched by a practising clinician. Douglass and Moustakas (1985) suggest the heuristic position retains the essence of the person in the experience rather than the essence of the experience which is the endpoint to phenomenological inquiry (Crotty, 1996). This heuristic position was recognised by van Manen (1997) in drawing up personal descriptions of lived experiences, the phenomenologist knows that one's own experiences are also the possible experiences of others. Nurses have a tradition of using HP as a research methodology because it seeks to uncover truth and consider the everydayness of lived experience. Awareness of all the researcher brings to the study, in their role, their preconceptions and their own lived experience is made explicit through reflexivity.

4.5.3.1 Excerpt from Reflexive diary Oct 2020

I am a participant in my own research, exploring others' meanings while grappling with my own as a result of my own experience of the subject being explored. I am aware I have an

emotional investment in this research and the research relationships I will forge. Although I have a desire to understand others' experiences, do I hope they will be the same as mine? Am I legitimising my own interests around what nursing is and should be? Will I craft stories to fit my own narrative, hearing words that ring true, missing what others would interpret with different emphasis. Yet my pre-existing knowledge coming to this research area enables questions to be asked, and answers to be heard that develop empathic relations with participants in a hope to portray their lived experience. There will be some people I like, relate better to than others, agree or disagree with which demonstrates the value of ongoing examination of the research relationship.

4.6 Member checking

Member checking or participant feedback is the process of returning data to the participant in order to enhance the rigour of research (Bradbury-Jones *et al.*, 2010). It is widely used in interpretive phenomenological studies (Lillibridge *et al.*, 2002, Milne and McWilliams, 1996) and is part of the COREQ checklist for reporting qualitative research (Tong, Sainsbury and Craig, 2007). Crowther (2016) suggests it is necessary, following crafting the story from the data, to check if it reflects what the participant wanted to say. However, member checking is not the pinnacle of expressing rigour in Heideggerian phenomenology. It is in fact incongruent with Heideggerian phenomenology and conflicts with the values of interpretivism (McConnell-Henry *et al.*, 2011). Through the hermeneutic method, data was interpreted by the researcher and is a version of events. Heidegger (1995) recognised that understanding is only ever “on the way”; there is always the potential for new findings to emerge from the data, so findings are merely interpretations. The interpreted data reflects the researcher’s insight so member checking will not validate it. For this reason, member checking was not used in this study. The decision not to use member checking was affirmed following my first participant interview with Andrea (pseudonym). I had technical problems that meant I was unable to record the interview. I therefore took notes while Andrea answered the questions, and following the interview I wrote a narrative from the notes. In order to check if Andrea felt it was a true representation of what was shared, I returned my notes to her. She replied to say reading through the transcript had made her feel embarrassed that she had become

emotional when describing her experience of supporting people with breathlessness during the interview and she was apologetic. In returning the transcript to her I had exacerbated her discomfort, when she recounted a challenging clinical situation. Returning the transcript forced her to revisit this discomfort leaving her self-conscious. From an ethical perspective I have a duty of care to protect all participants from further distress, so this experience compounded my belief that member checking should not be part of this study.

4.7 Methods

Smythe and Spence (2020) suggested on the HP “way” there is an openness beyond a logical step by step guide, Heidegger goes back to the Greek to explain “method” as a way of access. So, the word method means “way” from here to there, heading toward something. The methods chosen for this project, from in-depth interview to my adaptation of Thompson and Crowthers (2020) analysis were indeed the way to unconceal the phenomena and new knowledge from the participant experiences of supporting people with breathlessness. These will now be outlined showing ‘the way’ this project was undertaken.

4.7.1 Ethics

In engaging with others' lived experience, we are being-with and being open to that story. This calls upon practice from an ethical standpoint valuing and respecting the experience shared with us. Heidegger informed us that a

‘phenomenon, the showing-itself-in-itself, signifies a distinctive way in which something can be encountered’

(1962, p54).

The ‘distinctive way’ Heidegger refers to is the phenomenological attitude that enables implied meanings to become explicit, to be seen, heard and reflected upon. Every decision made in life has ethical positioning, underpinning and consequence but as a researcher this

position needs to be made explicit. As the researcher I tried to be consistent, non-judgmental and fair when interviewing participants and in managing the data. In Hermeneutic Phenomenology studies the requirement to “unpack who we are” (Dibley *et al.*, 2020 p89) through our presuppositions and reflexivity help to be open to participants' ways of thinking, to create an atmosphere of trust. Gaining insight into another's lifeworld to reveal meaning of a given phenomenon requires ethical approval in order to protect participants, demonstrate the benefit of the research and the opportunity for new knowledge. Approval ensures the research is designed and conducted in accordance with agreed ethics principles.

Asking participants about their experiences of supporting people with breathlessness required them to reveal their lived experience, the details of which were gifted for the purpose of the research. It is therefore only respectful and ethical to approach the whole research project with thoughtful consideration. The questioning asked them to recall these situations and share their vulnerabilities by being fully embodied in their experiences. Heidegger (1962, p54) argued that ‘verbal articulation is given by the fact that existing is bodily existing’, that is in talking about an experience that has happened, the person has embodied that experience and relates to it. Within a phenomenological framework the researcher is called to ‘be there’, open to another's story, valuing and respecting their experience.

The requirements of all universities are for research to meet ethical standards in design and conduct in order to carry out doctoral research. As my participants were nurses (rather than patients) and were recruited by asking nurses to opt into the project (rather than being approached directly) University Research Ethics Committee (UREC) ethical approval was required for this study. The process for this not only required a completed application form but a detailed examination of the ethics approval, participant information sheet (PIS), interview schedule, GDPR Privacy notice and consent form. These are all included in appendices 1-5).

The ethical threats considered for this study were in relation to interviewing. Consideration was made that the use of romantic interviewing (Alvesson, 2003) to achieve empathetic connection with participants might conceal the asymmetry of the relationship between researcher and participant and could lead to disclosure from the participant of highly personal information. This was mitigated by reminding participants of their informed consent and autonomy to withdraw from the study. Including excerpts from a reflexive diary sought to offer transparency regarding my position as researcher. The desire to achieve rapport to connect with participants to achieve a reflective, thoughtful interview to gain experiential data was balanced against a desire to respect their privacy and choice in what they shared at interview. The PIS (appendix 2) set out details of the study including the request to share an experience when they supported a patient with breathlessness, this gave the participants time to think about what they would like to share prior to the interview. There were no concerns raised by the participants about this. Reflexive accounts demonstrate my experience as the researcher in navigating this position, which was different in each interview (seen in appendix 8). There was also consideration that if the participant was to disclose poor practice and the researcher had to disclose this, this would undermine the trusting relationship established. The informed consent made clear the professional obligation to adhere to the NMC Code of Conduct for both researcher and participant, acknowledging the autonomy of research participants to withdraw at any time. There were no concerns at the interviews about poor practice with any of the participants. Ethical approval was granted following the first application.

4.7.2 Recruitment

4.7.2.1 Participant characteristics

There was no specification of age, years of experience, gender or geographical location of the nurses recruited to the study, but they were all registered nurses in the UK with a community caseload of respiratory patients. This is because the focus of the study was

about the participants' experiences yet their dasein provides context to these experiences. Those unable to partake in an interview speaking English were not recruited to the study. Therefore, participants for this study were recruited through purposive sampling. This is consistent with hermeneutic phenomenological research because it enables selection of participants who have experience of the phenomenon of interest which is most likely to provide data which addresses the research question (Dibley *et al.*, 2020).

4.7.2.2 Sample size

Unlike positivist research (Dibley *et al.*, 2020), there is no formula to identify optimal sample size in a hermeneutic phenomenology study. Positivist research aims to answer a specific question with quantifiable results therefore sample size is often calculated statistically. A hermeneutic phenomenology study does not aim to explain why, measure or compare or claim proof in this way. Dibley *et al.*, (2020) offer the following criteria regarding sample size to consider:

- The overall purpose of research
- The relationship between the rarity of topic and sample size
- The depth and completeness of data being collected
- The method for analysis being used

In answer to these criteria the purpose of this research is to gain insight into the experience of caring for people with breathlessness, to engage with and think about this meaning. It is not to prove or disprove or provide irrefutable evidence but to

“...provoke thinking toward what “is”, requiring smaller participant numbers who can provide rich data”

(Smythe *et al.*, 2008, p1392).

Accessing participants willing to talk about their experiences of supporting people with breathlessness proved quite challenging and to an extent made it a rare topic influencing the opportunity for purposive sampling. However, it was important to find a sample size big enough to reveal similarities in shared experiences but also the differences that demonstrates the uniqueness of each participant's world. While this study does not try to achieve data saturation, it aims to capture in depth data demonstrating philosophical consistency and completeness to explore the experiences of CRNS's working across the field for interpretive analysis. Malterud *et al.* (2016) identify a specific sample with a focused aim for the research, dialogue between the researcher and participants and case approach to analysis are features of qualitative research with the small sample size giving greater "power" to the study, differing from positivist research.

Interviews were in depth generating large amounts of data so rather than shallow descriptions of the phenomena of interest, the richness and depth of data enabled deep phenomenological analysis. The intention to craft stories as part of the analysis for each of the interviews was a factor in optimising sample size. Smythe (2011) identifies that seeking to honour each participant by working with their data to embody the analysis inevitably results in an upper limit of participant recruitment. The confounding factor at the time of recruitment was the COVID-19 pandemic (recruitment Dec 2020- July 2021) which most likely limited the opportunities for recruitment and the willingness of participants to engage initially but prompted me to revisit the ways potential participants could be identified.

With this in mind, once twelve participants were recruited to the study it was agreed with the research team these interviews would provide a significant body of data for analysis.

4.7.2.3 Excerpt from Reflexive diary July 2021

[Having just completed the online HP course] I feel confident that I will stop at 12 interviews as I recognise it is not about the number of interviews but the depth of data that I have, and

actually crafting the stories from for 12 interviews will give me a richness of data to analyse and interpret.

4.7.2.4 Methods of recruitment

The population of interest was CRNSs working in the UK so to access this population the social media platform Twitter and the ARNS (Association of Research Nurse Specialists) were used. ARNS is a group of more than 1660 nurses within respiratory care across Great Britain. ARNS agreed to promote the study by using its Twitter account and monthly 'E-Shots' (newsletter) to its members.

As an existing user of Twitter, I sought to expand my following and followers within the field of respiratory care when preparing for recruitment. In this way when I tweeted the recruitment banner for the study (see fig 3) it was seen by several hundred respiratory nurses. Many people on Twitter generously retweeted the recruitment banner so that in total I recruited seven participants from Twitter. Of these, three people were recruited through snowballing discussions with other participants. One participant was recruited following publicity from the Monthly 'E-Shot' from ARNS where the same banner was posted. One participant was recruited following a conversation directly with the researcher. The benefit of snowballing was that participants that might have not been accessed (because they did not use Twitter or were not members of ARNS) could access the research.

The use of social media platforms for recruitment to research projects has become increasingly popular (Leighton *et al.*, 2021). During the pandemic other opportunities to recruit face to face such as professional conferences or regional meetings were either cancelled or continued online due to social distancing and recurrent lock downs. This limited the opportunity for would-be participants to express interest in the research project. Whilst there are limitations with using Twitter (see limitations in chapter 8) it enabled successful recruitment of 12 participants.

Fig 3. Recruitment banner



4.7.2.5 The philosophical implications of remote data collection in a study underpinned by “being with”

Due to the timing of data collection (COVID pandemic 2020-2021) I was unable to consider the option of face-to-face data collection. There were inevitable disadvantages of this, particularly apparent in a study underpinned by ontology and “being with”. The most obvious disadvantage was an inability to connect with my participants face to face. Although we were all getting proficient in speaking on online video platforms by this time, it was still challenging to build rapport in the absence of face-to-face contact. However as there were no alternatives, this compromise was very much accepted in the context of the time and was generally embraced by both parties.

Attending the online HP course (Crowther. and Thomson) in July 2021, which I initially approached with reservation (due to the absence of face to face engagement) I became aware that this did not have to be a barrier to meaningful engagement. Immersion in the methodology and Heidegger's philosophy, meeting a truly international cohort of peer

researchers and engaging in active learning throughout the course showed me that the lack face to face did not need to be a barrier to genuine involvement.

I am aware of the irony of “being-with” yet separate. However, proximity is not part of the definition. In relation to the practice setting being-with is a

“specific moment of engagement between a health professional and a patient whereby the patient has the opportunity to examine and express their thoughts and feelings [relating to their imminent death]”

Haroldsdottir, 2011p1357

I set out my intention to “be-with” the participants to examine and express their thoughts and feelings about caring.

4.7.2.6 The process of recruitment

Nurses who expressed an interest to participate in the research either direct messaged on Twitter or emailed depending on how they were recruited. If they Direct Messaged, they were asked for an email address and were then emailed a participant information sheet (PIS appendix 2) and privacy statement (appendix 4) which included contact details for the research team. No additional questions were asked by any of the participants prior to taking part in the research. All nurses who made contact progressed on to complete the research interviews. There was a contingency that if there was over recruitment to this study, participants would be selected based on their geographical location to enable a sample that was geographically spread so that all parts of Britain are represented. This was in a hope to avoid overrepresentation of one part of the country where particular practice might be characterised. If there was under recruitment, further postings would be made on Twitter encouraging retweets and sharing of the original post. The email addresses supplied by nurses interested in participating were kept separately and securely from the data, with the intention that those who decided not to participate would have their addresses removed.

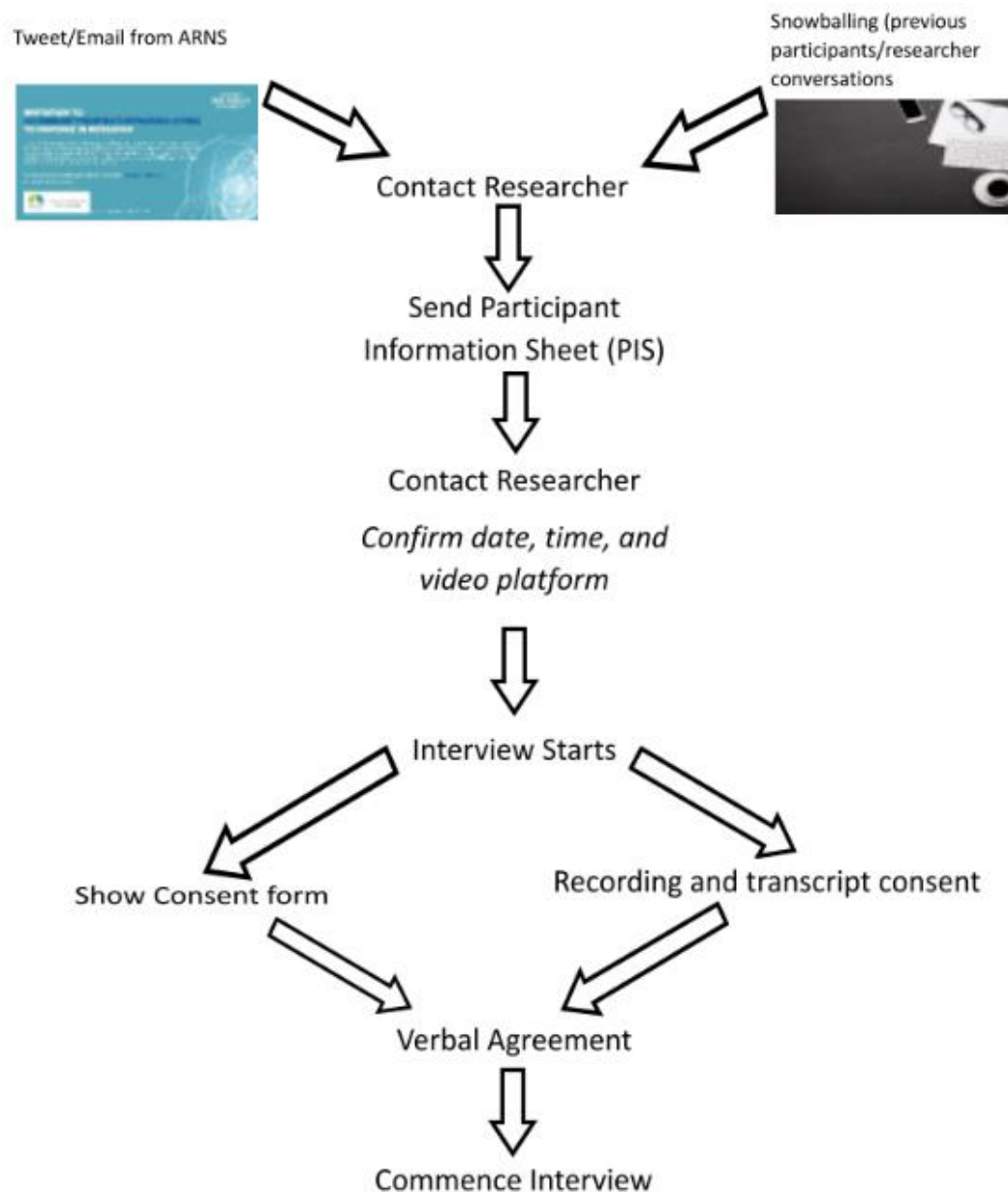
Participants were contacted within 2 weeks of them receiving the participant information. On agreeing to participate, a convenient time and date for an interview was arranged. The participant was given the choice of online computer platforms and an invitation for the agreed time and date of the interview was subsequently sent to the participant. The recruitment process is set out in Fig 4.

The participant information sheet (appendix 2), given to each participant before making a decision to sign up for the project details possible disadvantages of taking part in the research including recalling challenging or emotional experiences (sign-posted to the RCN or their occupational health department). Although one participant did become upset (Andrea in Interview 1) there was no evidence any harm came to them in participating. In depth interviews were held with the researcher on the internet video platforms of choice (Zoom, MS Teams, Google Hangouts) their duration ranged from 45-80 minutes.

4.7.2.7 Excerpt from Reflexive diary on research recruitment 8/12/20

"I was excited to tweet my recruitment banner for the first time at the beginning of November 2020. However, despite several weeks of subsequent tweets there was little response. I have had one nurse who I am interviewing on Thursday. In Supervision we discussed the lack of engagement and realised that in order to talk about this subject and personal experiences the nurse needs to be relatively self-aware, reflective and self-confident. Therefore, to find somebody who is a community respiratory nurse who is confident and competent and experienced and is prepared to partake in research narrows down the field greatly. In understanding this I can see why I am finding recruitment quite challenging. We explored the options for increasing the recruitment to non-respiratory nurses. I feel that it is still early days (one month) and I should give it a bit more time."

Figure 4 Flow chart of recruitment, consent and interview process



4.7.3 Data Collection: Interviewing

For Heidegger, conversation and dialogic exchange are the cornerstone of understanding of the world (Heidegger, 1962). Speaking and listening to others involves ongoing interpretation and co-construction, therefore interview as a means of data collection is the method of

choice in hermeneutic phenomenology, where phenomena cannot be observed directly (Kvale and Brinkmann, 2009). An in-depth interview attempts to uncover themes of the lived everyday world from the participants' own perspectives expressed in normal language, without quantification (Brinkman and Kvale, 2015). This fulfils the aim of my research project and is consistent with an HP approach. Brinkmann and Kvale (2015) describe the interviewer as either a “miner or a traveller” (p57) referring to their epistemological approach. The miner uncovers knowledge so takes a descriptive, positivist approach whereas the traveller interprets the experiences and knowledge, enabling co-construction in the interaction between interviewer and participant. This co-construction or fusion of ideas explored in Gadamer’s work (1975) describes the integral interaction as the conversational process unfolds. As a hermeneutic phenomenological researcher, the notion of the traveller seeks co-construction and interpretation to new understanding of the phenomena, consistent with the chosen method.

The purpose of qualitative interviewing is for the interviewee to share their own experience of the phenomena of interest describing rather than quantifying specific rather than generalisable experiences in their lifeworld. Therefore, interviewees responded to subject areas with varying sensitivity demonstrating the individuality of each participant. As the interviewer, I tried to approach each interview with openness and naivete rather than any ready-made interpretations but aware of my own presuppositions (shared in chapter 2). The interview was a reciprocal space for exploration, learning, reflection and was a positive experience for both the researcher and participant. As it is uncommon for someone (nurses especially!) to be listened to as they share their experiences and views on a topic, many of the participants expressed their appreciation at having this opportunity. This was a process of catharsis and given the unique nature of the interaction within each interview, knowledge was produced by the interaction itself. As Brinkmann and Kvale (2015) suggested, at every interaction with each different interviewer and participant, a different interaction will be created, and different knowledge revealed. Therefore, it is important to recognise that

hermeneutic phenomenological interviews seek to reveal this unique encounter between researcher and participant that will not be generalisable but offer new understandings.

4.7.3.1 In-depth interviews

In order to carry out this research and explore the phenomenon of interest, participants were interviewed so they could share their experiences of supporting people with breathlessness through their stories. The use of in-depth interviews as a research method will now be explored. An in-depth interview attempts to understand the lived everyday world from the participants' own perspectives. Consistent with the ethos of the methodology, I tried to achieve a feeling of trust between myself and the participant. Reviewing the Participant Information Sheet (PIS) (Appendix 2) enabled each participant time to think about their role in caring for patients with breathlessness and be aware of the questions they would be asked and to think more deeply about the experiences they chose to bring to the interview. Vandermause and Fleming (2011) consider 4 characteristics of the HP interview which I have applied to this research project in Table 2.

Table 5 The 4 Characteristics of the HP Interview (from Vandermause and Fleming (2011))

Characteristic of HP	Explanation	Example in this research project
Setting the tone of the research	Conversational tone, encourage trustworthiness, open questions that ask about specific events and apply to the others that follow	My 3rd question asks: Can you tell me about a specific time you cared for someone who was breathless?

Incomplete sentences	Interviewer to guide rather than lead the discussion to uncover phenomenon in a naturalistic way, therefore allow time for participant to respond	“Unfinished...?, can you tell me more?” (Int 3) “I wonder how this made you feel?” (Int 4)
Looking for assent	Interviewer questions own understanding periodically	“Are you saying there's not enough support in place?” (Int 3) “Is it about managing expectations?” (Int 4)
Returning participant to the story	participant may leave the story if it is uncomfortable so bring them back to help the story proceed	“I am interested in how you felt in the situation when you said you go into it with slight dread?” (Int 7)

Enabling participants to feel heard in the interviews by giving them the platform to respond to open questions yet share the experiences pertinent to the research project was challenging as a neophyte researcher. Often participants described what they did, detailing their actions

rather than how they felt when caring for people with breathlessness. On these occasions I asked again about their thoughts and feelings which mostly refocused them.

Despite attempts to enable open and free dialogue, it is important to acknowledge interviewing differs from conversation as there may be a power asymmetry in the research interview process. Brinkman and Kvale (2015) suggested that the interview can be a one way, manipulated dialogue where the interviewer has the monopoly of interpretation. However, as Wolgemuth *et al.*, (2015) and Roulston (2010) identify, this is structural power and does not need to be an exertion of power by the interviewer, it can be diminished when adopting a constructionist paradigm in a collaborative meaning making experience. In fact, interviews conducted from a constructionist paradigm have been noted by interviewees as therapeutically beneficial (Carter. *et al.*, 2008, Hiller and DiLuzio 2004). I did attempt to address this power asymmetry by acknowledging with the participants that I am also a CRNS, so we were peers, despite my role as researcher in the project. This reduction in power asymmetry was supported as at the end of the interviews, several of the participants commented how they appreciated being asked about what they thought about the subject, providing them an opportunity to reflect. It enabled connection with another nurse (i.e., myself as researcher) interested in the same area of clinical practice and they wanted to help with the research. These comments compare with Wolgemuth *et al.* 's (2015) results when they analysed the benefits of participating in qualitative research.

Although the choice of how to conduct the interview had to be adapted in response to restrictions at the time of the data collection due to the pandemic, it had always been my intention to conduct telephone interviews in favour of face-to-face interactions in order to overcome costly and time-consuming travel for what was hoped to be a geographically dispersed cohort of participants. Musselwhite *et al.* (2006) supported this view about telephone interviewing and showed that it enabled economic use of resources, it is convenient for both parties, positive relationships can form between the researcher and participant and the quality of the data collected can be improved. These factors also applied

to video platform interviews. The video platform provided the best of both approaches, being able to see each other but remaining in our own environments, reducing disruption, ensuring social distancing and enabling time efficiency. Due to participants being spread across the UK this method enabled access to all participants. In person, face-to-face interviewing has traditionally been considered the gold standard (Bryman, 2008), although Siemiatycki (1979) concluded that the quality of the information obtained in telephone and in-person interviews was comparable and, more recently, this was supported by Sweet (2002) when used for interpretive phenomenological research. Mealer and Jones (2014) identify the 4 types of non-verbal communication which are proxemics, kinesics, chronemics and paralinguistic. Proxemics is the way the individual communicates by controlling their environment and Kinesics: the use of posture, gesture and facial expression are all lost in telephone interviewing which can be argued as a disadvantage (Novick, 2008). However, these aspects of non-verbal communication can be maintained using video platforms with the choice to maintain eye contact and identify non-verbal cues which can enhance the interview for both parties. Although the video interviews were not analysed specifically in regard to proxemics and kinesics, the non-verbal communication contributed to the attunement of the interview (which is discussed in chapter 5, 5.3).

Literature concerning online interviewing has been slow to emerge highlighting drawbacks mainly due to technical challenges either due to equipment or internet connectivity (Deakin and Wakefield, 2013). Whilst this can remain a challenge in some geographical locations, this research is now 9 years old and in 2021 (when I conducted the interviews) most of the UK was covered by 4G and 5G improving connection with 87% of the population (55.5 million people) having Smartphones (Statista.com). Denscombe (2003) recognised online interviews can be comparable to traditional face-to-face interviews with an opportunity to build rapport, enabling the researcher to engage with participants. The benefits of accessing harder to reach populations (due to geographical location), of finding a mutually convenient time (some interviews took place in the evenings and weekends due to full time working) and

of taking up minimal time of the participants that Deakin and Wakefield (2013) identify rang true in this study. As the pandemic continued, video platforms rapidly became a usual part of day-to-day life in the NHS where meetings with other Health Care Professionals, courses for professional development, conferences and consultations with patients commonly took place on-line. The NHS adopted MS Teams as the platform of choice and users quickly became proficient in using it effectively. Not only does it enable face to face engagement between individuals, but it also enables sharing of files and works with any smart technology. This undoubtedly helped participants who were mostly familiar with the skills required to engage in such an interview platform, normalising this new way of working and engaging with each other. The two main disadvantages noted were that with the interview taking place in the home, the flow of the interview could have been disrupted as the onus was on the participant to find a suitable location and was not within my control as the interviewer. The other drawback was building rapport with participants who were more reserved and less responsive, creating more of a challenge to respond to non-verbal cues. Lo Iacono, Symonds and Brown (2016) identified that this platform suits those with outgoing personalities who are more comfortable talking freely, disadvantaging those more reflective, reserved individuals (although silences and space within the interview were left, space for non-verbal communication seemed to be more challenging using this platform). These aspects of the interview process made known through the literature, as well as perspectives that arose from a pre-understanding and pilot interviews, greatly informed my approach to the participant interviews.

4.7.3.2 Pre-understanding and Pilot Interviews

In keeping with HP methodology, I conducted two pilot interviews and was interviewed as the researcher by one of the supervisory team which gave me the opportunity to experience both carrying out and participating in the interview process prior to the research interviews. As a novice researcher this was important reflexively to consider my own position going into this research.

4.7.3.3 Reflexive diary 3/11/2020

Despite having written these questions I found they were thought provoking and I considered new, different aspects of my position that I have not considered before. For example, the idea of using a difficult experience of caring for somebody who was breathless and making me more aware of the needs of other nurses in the team, of being more authentic: a real human being witnessing the distress person-to-person. Also, it helped remind me and reinforce the value of relationships, both therapeutically with patients as well as supporting colleagues.

It never fails to surprise me how emotive and present the feelings still are for me of witnessing such extreme distress of another human being and I feel this will carry me into the future, feeling the value of this research.

Chenail (2011) recognised pilot interviews for the researcher and others, as a strategy to address the position of the researcher who becomes the key research instrument in qualitative interviewing. This opportunity did indeed allow me to appreciate the vulnerability of the participants when sharing personal thoughts and feelings that arose during the interview and to gain a deeper appreciation of the challenge of sharing knowledge on this topic. It highlighted my perspectives that might influence the study, for example my belief that caring for breathless patients can be challenging and is not an aspect of the respiratory nurse role that is well supported. While these preconceptions cannot be bracketed out or removed, foregrounding them and documenting them enabled the fore structures of understanding to be made explicit on entering the hermeneutic circle.

The final version of the interview schedule (appendix 3) was achieved following pilot interviews, with two CRNSs recruited from my current place of clinical practice. This provided the opportunity to clarify ambiguous questions and highlight questions that were received as challenging. For example, when asked 'What more could be done to support breathless management in clinical practice?' The first nurse felt this question sought to highlight the limitations of her own practice and gaps in her knowledge. She reflected that

nurses who came forward for the purpose of this study would most likely be self-confident and assured in their practice because these questions were searching and exploratory rather than functional (something that was highlighted through conversation with my supervisory team in 4.5.2.6). This was highlighted when the second nurse chose to answer the question “can you tell me about a time you cared for someone who was very breathless?” functionally (detailing what she did, what happened rather than how she felt), and despite attempts to steer her to share emotional components of her story she was keen to keep a medically informed focus. This highlighted what would be an ongoing challenge when interviewing participants with them also explaining what they did rather than how they felt. This challenge is consistent with Johnson’s own research (2000) emphasising that even the most skilled interviewer might struggle to elicit answers that focus on the emotional rather than practical experiences. My experience with pilot interviews is consistent with Kim’s (2011) 4 findings. She found issues and barriers in recruiting (the issue of the confident nurse prepared to be questioned about practice and therefore feel challenged), engaging oneself from a phenomenological perspective (the skill of Hermeneutic interviewing), the epoche process (establishing my preconceptions and fore structures of understanding when asking, listening and responding to participants and the opportunity to modify interview questions. While there were few modifications made as a result of the pilot interviews, this opportunity enabled me to consider the perspectives of my participants, rephrasing questions where needed.

4.7.3.4 Excerpt from Reflexive diary: 1st pilot interview 14/10/2020

[The interview] went really well and I feel really encouraged and pleased with the outcome. I was keen to elicit meaning from what she said. I am aware this could be hard being a community respiratory nurse myself and confident with the content discussed, I was aware I might not pick up the nuance and the meaning of specifics that was said, I enjoyed the interview and felt comfortable letting her speak. I am aware that talking to somebody I already know is in some ways more comfortable because the connection and confidence in the relationship is there. However, there was a point when she looked down, blushed at being asked what more could be done in the service, perhaps because she felt a gap in her knowledge. It felt like she was embarrassed at this, though I did not feel she had anything to

be embarrassed by. When I do interviews with people I don't know, maybe they will be more comfortable to share their limitations in knowledge.

[The nurse] said she felt it required quite a lot of self-confidence to have this interview/conversation.

4.7.3.5 Excerpt from Reflexive diary: 2nd pilot interview 21/10/2020

The nurse in question answered all questions in a functional way rather than sharing personal thoughts and feelings around the subject. This frustrated me and when I rewatched the interview I can see that I continued to push her without acknowledging or validating what she said. I think I was trying to get her to say something that I wanted her to say rather than listening to her.

I'm not sure why, maybe it was this subliminal frustration, but I seemed to feel a need to write a lot down and when I rewatched the interview I can see maybe it was disjointed because I wasn't looking the nurse in the eye and kept focusing on my note taking.

My learning from this interview is that I must keep an open mind when a candidate's answers diverge from my own. I am doing this research to find out the perspective of others, not to prove myself right so I want to keep a truly open mind. Yet I am aware of the subliminal dissatisfaction I felt at not hearing what I wanted to hear.

4.7.4 Interview schedule

The in-depth interview schedule was developed following consultation of the literature (Vandermause and Fleming, 2011, Brinkmann and Kvale, 2015, Dibley *et al.*, 2020) primarily to meet the requirements for university ethics approval. Provision of a full interview schedule to the ethics committee demonstrated what the participants would be asked in the research interview, reducing the risk to participants of being asked anything unreasonable.

Hermeneutic Interviewing question schedules are brief and simple, reflecting the components of the research questions and are generally less structured. They give the opportunity to flexibly follow up questions as the participant leads.

Given the nature of online interviewing (rather than in person), it was important to establish a rapport between researcher and participant. For all (apart from 1 participant) this was the first meeting so in order to build rapport participants were initially asked to tell me about themselves, their career to date, their clinical interests and the team they worked in, to give them an opportunity to share who they were, what matters to them, alluding to their *dasein*, historicity and thrownness. As appendix 3 demonstrates, the interview was essentially composed to ask broad questions, focused questions and follow up questions. The pivotal research question “can you tell me about a time when you cared for someone who was breathless?” was designed to appear approximately twenty minutes into the interview with the intention the participant would talk broadly about breathlessness before focusing on their specific experience. This question asked the participants to share a story about their experience, in keeping with the phenomenological approach of researching lived experience to elicit their own description. Benner (1994) describes this as the ‘critical incident’ approach to questioning where participants are asked to tell a story that stands out for them because of what it means about the phenomenon in question. This will often be an experience that is particularly memorable or profoundly affected them in some way (Dinkins, 2005). Johnson (2000) identified that participants are often tempted to give a factual account where the practical, interconnected experience of their world is revealed. This proved to be the case where the participants felt more able to share what they did rather than how they felt. I tried to keep the interview focused on the experience by paraphrasing what had been said and clarifying uncertainties but often, as was Johnsons’ experience, I asked the participant more specific questions to focus on their experience.

4.7.5 The interviews

The consent form was shared at the beginning of each interview and verbal consent was gained, drawing the participants’ attention to appendix 5. Data was stored electronically on a secure, university password protected Google Drive and will be stored until completion of the thesis.

As Mealer and Jones (2014) suggest, each interview began with “innocuous questions” (p34) to allow time to connect by sharing similar work backgrounds and build understanding. The importance of building rapport to gain the best HP interview was apparent, so starting the interview informally put the participant at ease and set the tone for the interview.

Interviews were conducted once with each participant. This method is most commonly used in research interviews (Holloway and Wheeler, 2002) and enabled the opportunity to explore the aspects of the research question sufficiently with all participants. I am aware that each interview is a moment in time, an encounter between the participant and myself as the researcher that enables co-construction of knowledge. Follow up interviews might have progressed thinking on the subject for participants. This could have led to more in depth sharing of their thoughts and feelings relating to their experiences of supporting people with breathlessness but there is no guarantee that this would be the case. Each participant was asked at the end of the interview if they wanted to share any further thoughts they had regarding the subject, to offer an open opportunity. Time restraints might have been a barrier to arranging second interviews with the participants.

4.8 Data analysis

4.8.1 Transcribing

Both MS Teams and Zoom have a facility to record and transcribe each interview. Whilst the transcripts needed careful scrutiny and amendments due to dialect and enunciation, each transcript provided a good starter and initial draft from which to produce the final version. Personal and identifiable data (names, organisations etc) were removed from the data to protect the privacy and confidentiality of the participants. Each participant was given a researcher assigned pseudonym (fig 4). Names rather than numbers add to the richness of the text emphasising the human situatedness of the stories. Vanderamus and Fleming (2011) advocate asking each participant to choose their own pseudonym in order for it to be

meaningful yet achieve anonymity. This was not done in this project, but the names chosen sought to reflect the self-identified gender, nationality and age of each participant. The names of places (towns and hospitals) were omitted and vocalised pauses were removed so that the narrative flowed smoothly. This is consistent with guidance from Crowther *et al.* (2016) when reviewing interview data to craft stories. There was some consideration to use specialist software to assist with organising the data for coding and analysis. However, the learning curve to understand effective and helpful use of the software was felt to be steep and despite the large amount of data, it was felt time was better spent reading and rereading the data as a whole, or dwelling with it (Goble *et al.*, 2012). Without the distraction of learning a new data analysis platform, I was able to consider the attunement of the interviews and reveal the phenomenon through analysis.

Table 6 Profile of Interviews

Interview number	Pseudonym given	Date of interview	Origin of recruitment
1	Andrea	Dec 2020	Twitter
2	Belinda	Feb 2021	Snowball from first interview
3	Carrie	Feb 2021	Snowball from conversation
4	Deborah	Feb 2021	Twitter
5	Esther	Feb 2021	Snowball from first interview
6	Fiona	Feb 2021	Twitter
7	Gwen	May 2021	Twitter
8	Hilary	May 2021	Twitter
9	Irene	May 2021	Twitter
10	Janet	May 2021	ARNS Email

11	Katy	June 2021	Twitter
12	Linda	July 2021	Snowball from Int. 11

Table 3 shows details of the interviews. These are presented in chronological order, undertaken between December 2020 and July 2021. In Appendix 8 there is a brief biography of each participant to acquaint the reader with each nurse's professional journey and personal priorities in care as they described at interview. I chose to ask each nurse to tell me about themselves and what brought them to their current role rather than ask them specific demographics. As a result of this they each gave a different account, reflecting their own priorities when describing themselves.

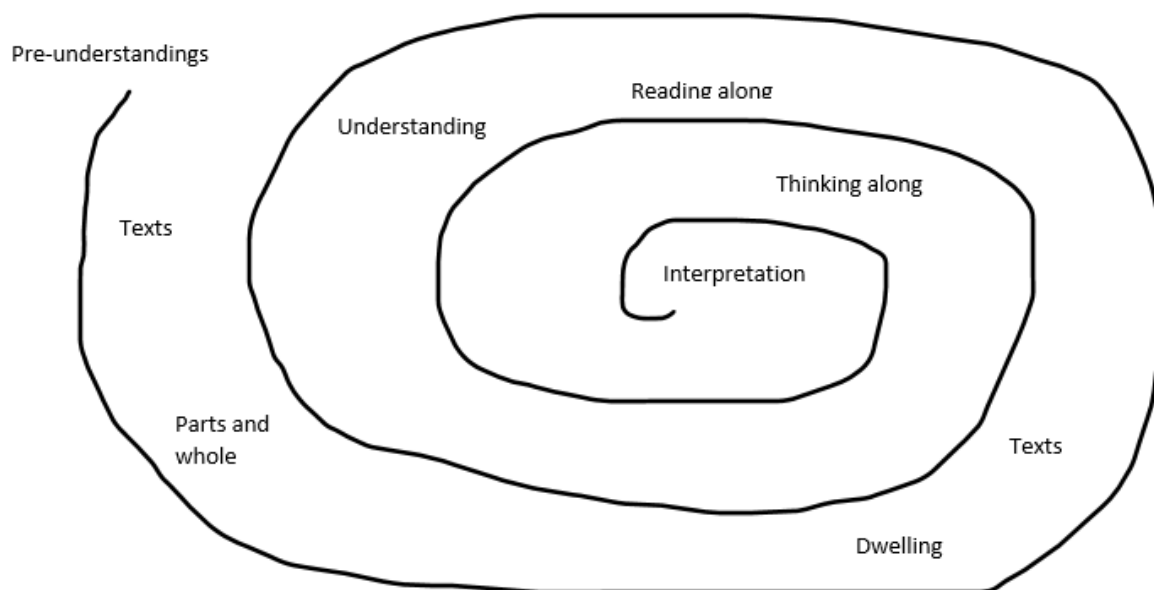
4.8.2 Method of Analysis

According to Heidegger (1962), phenomena are essentially withdrawn, covered up and even disguised in everyday life. They are taken for granted in a pre-reflective natural attitude and go unnoticed within lived experience. Although phenomena can never be fully revealed, adopting a phenomenological attitude can illuminate that which eludes us, moving from the ontic to the ontological. A phenomenological attitude, challenged my naturalistic, taken for granted approach to the data enabling me to stretch my thinking beyond what was already known.

Data analysis in HP is an evolving, iterative process that seeks to unconceal meaning through interpretation of lived experience (Crowther and Thomson, 2020). This involved a 'to-and-fro' from the crafted stories to the literature and to Heidegger's work which put me within the hermeneutic circle (Fig 4). The hermeneutic circle is a metaphor for the cyclical movement of this understanding, interpretation and reinterpretation of data between the whole and the parts then back again until new understandings are revealed. It is not a linear

process but involves deep thinking and dwelling with the data and literature. It shows that life is not lived in a vacuum but that our lifeworld, and that of each participant gives self-awareness but also context, to reveal new insights through interpretive discourse (Smythe, 2011). In the dialectic play between the participants' lived experiences and myself as the researchers' own practical understanding, I recognise that interpretation comes from the data and what I bring myself to the interpretive process.

Figure 5. The Hermeneutic Circle (Dibley *et al.* 2020, p128)



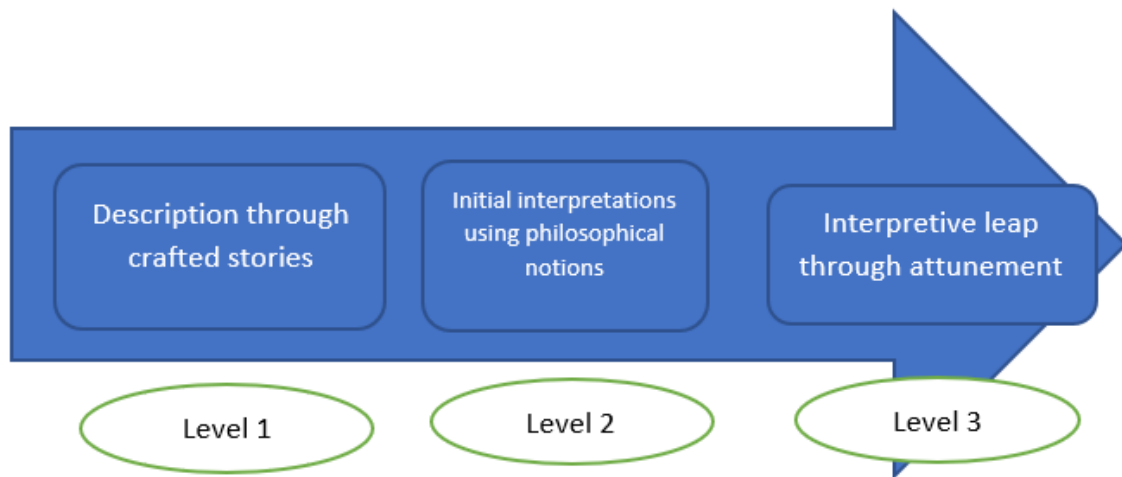
This fluidity of to-and-fro from literature to data to philosophical texts was difficult and as a novice researcher was definitely the most challenging aspect of the whole research study. Being encouraged to "trust the process" left me feeling somewhat at sea with little or no anchor. Sloan (2002) referred to three moments of interpretation within her research forming her analysis; the first moment was during her interviews, the second during interpretations of each individual narrative and the third were interpretations from narratives across her life's work. This resonated with me although I would suggest there were many more than three moments of interpretation. I was aware that at interview I responded to what was heard by

asking more questions, clarifying as thoughts formed, so that both the participant and I were shaped by the interview. My reflexive thoughts were recorded after each interview which was a further analytical tool, acknowledging my thrownness in each interview.

Gadamer (1975) warned that over reliance on one method [in research analysis] leaves what is meaningful hidden and is antithetical to the pursuit of truth or unconcealment. With this in mind, my analysis comprised three parts each of which further developed thinking and interpretation of the data. The first stage of analysis was achieved primarily by reading through the audio transcripts, watching the video recordings of the interviews which enhanced interpretation and led to crafting stories. The second stage of analysis, examining Heidegger's philosophical notions in relation to the crafted stories, revealed a new understanding of the experience of caring for people with breathlessness. From this, in reading and re-reading the crafted stories, in the third stage of analysis, I attuned to the experiences and began to see themes starting to appear. Gadamer (1975) suggested that to understand something is to apply it to our own circumstances, testing understanding against our own preconceptions. The "fusing of ideas" from my own pre-understanding with participants' stories arrived at this interpretation which is context specific and as Edwards (2022) suggests: understanding is a unique possibility.

Analysis of the data followed this iterative process but was essentially in three parts. Crowther and Thomson (2020) propose a model for analysis. They are clear that this represents their direction of travel rather than a lineal journey, affirming the to-and-fro described in the hermeneutic circle. While I have aligned with this model for analysis, I have adapted it to illustrate my own process of analysis as Figure 5 shows.

Figure 6: 3 stages of analysis (adapted from Crowther and Thomson, 2020)



These parts will now be described to demonstrate the process by which new understandings were revealed. Each stage will be explored to describe how interpretation shapes the analysis.

4.8.2.1 Crafted stories

The decision to craft stories came from extensive reading on the subject area (van Manen, 1990, Smythe. 2011, Crowther *et al.*, 2016, Crowther and Thomson, 2020) and undertaking the Hermeneutic Phenomenology course on-line (Hermeneutic Phenomenology Course, 2021) where the method was discussed at length. As human beings, the appeal of telling stories to bring alive phenomena has been a tradition for thousands of years (Lawrence and Paige, 2016) and fits with the premise of Heideggerian phenomenology to glimpse meaning in human experience (Crowther *et al.*, 2011). In HP there is acceptance there is no single or universal way to work with the data, Koch (1998) reminds us that this methodology is not about “what we do” but asking “what is going on”?

A crafted story is narrative crafted from interview data that holds the meaning for the participant to show the experience; keeping the story as a whole and speaking to the reader directly (Crowther *et al.*, 2016). Gadamer (1975) suggested that ‘understanding begins when something addresses us’ (p299). Inherent in Heideggerian phenomenology are the researcher’s understandings in the interpretive process, as van Manen (1997) reminds us an attuned researcher apprehends more than words in transcriptions, able to craft rich meanings from stories that resonate with the reader, describing and revealing the nuances of contextual experience. In dwelling with the data and crafting stories, light can be shed on ways of being, thinking and acting in the world that might be known but are covered up or forgotten. Crafting stories demonstrates the dialectic movement of method and methodology, moving the transcript from ontic description to ontological analysis informed by my own pre-understandings as the researcher. For Heidegger, (1962) truth is unconcealment (*aletheia*) not a hierarchy of truths (Crowther and Thomson, 2022). The crafted story speaks of what is told and what is heard at the given moment. HP accepts that phenomena are never fully concealed or unconcealed to anyone but draws attention to multiple meanings within the phenomena, drawing the reader to new understandings.

In order to craft stories from each of the twelve transcripts, extraneous details that did not add meaning to the story (for example what the weather was like, the medication regime) were removed (Crowther *et al.*, 2017). The sentences that seemed to hold meaning were kept, adding words in where sentences had been removed to link one section to another. Within this iterative, interpretive process and continually returning to the transcript, questions were asked “does this story ‘show’ the experience? “Does it still hold the meaning as gifted by the participant?” and “have we seen ‘more’ in the process of crafting up this story?” (Crowther *et al.*, 2011). The process of crafting stories presented the interplay between the parts and the whole story attuning the phenomenological stance. Each story presents an insight into a human experience that resonates. This ontological orientation of the stories coalesces to reveal new possibilities provoking further thinking and action.

Crafting stories within this HP study sought to address the research question "what are the experiences of CRNSs in supporting people with breathlessness? " illuminating human experiences that revealed multiple meanings and new understandings. The experience of crafting stories from the participant interview transcripts enabled a depth of interpretive analysis that might have been lost solely focusing on transcribed verbatim data. This process is illustrated in chapter 5 and five full crafted stories are presented in appendix 9.

4.8.2.2 Analysis using Heideggerian notions and emerging phenomena

While the crafted stories describe the lived experiences shared by participants, these experiences were the gateway to understanding the phenomenon of interest. As I crafted the stories from each transcript I returned to Heidegger's philosophical notions. Going back to the stories, several of these notions showed themselves. For each crafted story I wrote a commentary describing and interpreting what was speaking to me; highlighting the Heideggerian notions that were evident and emerging phenomena.

Heidegger's notions were a means to illuminate, shining a light on the natural attitude. From this process, I was able to look at the experiences described in a new way, illuminating the ordinary to make it extraordinary. The notions that were illuminated by the data were leaping in and leaping ahead as solicitude, thrownness, being-toward-death, the state of the uncanny, machination and being-with. Like Dibley (2022), I have no doubt there are other notions evident within the data, but in acknowledging my dasein and reflecting on my rationale for doing this research project, these were the notions that spoke loudest. I am aware there are no universal truths and that the fusion of horizons (Gadamer, 1975) between myself, and the participants is a co-creation of knowledge, uniquely fusing my position as nurse and researcher with that of my participants. While the second stage of analysis working with the Heideggerian notions revealed a depth of understanding of the

experience of supporting people with breathlessness, the third stage of analysis led me to consider the attunement of each interview which unconcealed the phenomenon of fulfilment.

4.8.2.3 Attunement as a means of analysis

Attunement is an important component in the analysis of interviews that is hard to quantify but that speaks beyond the engagement between researcher and participant. It betrays the participants' thrownness, their fallenness coming to the interview. It is pre-reflective, sensed and felt and is communicated through body language, voice tone, language choice and engagement. Heidegger calls it "the way" (1967) and is a way of being, listening and wondering (Smythe and Spence, 2022). Smythe and Spence assert that in "attuning-to" means to be "in" the world of the research:

"...not by careful planning but by finding oneself in a moment of happening. As such, in an interview, for example, one both influences the story being told and is influenced by its telling. It is an experience of immersion, of letting go, of soaking-up and waiting insights that come. Being-as-researcher means being open to whatever situation I find myself in, and always attuning to 'how I find my mood.'"

(Smythe and Spence, 2022, p23)

Smythe and Spence argued that working with the transcripts is so much more than seeking to identify themes but involves listening, questioning and wondering regarding thoughts to come. Attunement is dwelling with the data and in so doing tuning into the mood, picking up on the ontological experience within the interviews. The phenomenon of fulfilment was revealed as a result of attuning to the stories told. Descriptors of the phenomenon were identified throughout the transcripts of the 12 interviews. These were organised under eleven headings which were reduced down to five headings (figure 6, explored in chapter 5). Each shed light on different ways the participant CRNSs shared they experienced fulfilment. The descriptors were identified by Fulfilment-as (each aspect) in order to illustrate how fulfilment

was pervasive throughout the interviews. From this, and considering all three stages of analysis, conclusions were drawn regarding new knowledge that emerged from this process.

4.9 Conclusion

By seeking to address the research question “what are the experiences of CRNSs supporting people with breathlessness?” the execution of this research project has been described. The choice of HP has been justified as a way of revealing taken for granted meaning from the data. Each step of the project has been explored to give an audit trail demonstrating reliability and rigour in this research project, including reflexive accounts of my position as researcher. By moving on in the next 2 chapters focused on the analysis of the data, each stage demonstrates how new understanding was revealed.

Chapter 5 Analysis: Part 1

“The real voyage of discovery consists not in seeking
new landscapes but in having new eyes”

Marcel Proust 1923

5.1 Introduction

Crowther and Thomson (2020) identify the interpretive leap comes through an iterative process of in-depth hermeneutic work on the empirical data. For this project, this began with crafting stories from the data and was the first part of the analysis. In this chapter I use Gwen’s interview to demonstrate this process, reducing the interview transcript to a crafted story.

5.2 First stage of analysis: Crafted stories

Crafting stories was integral to the interpretive process that helped with initial descriptive analysis and tentative interpretations of the data. Crafted stories highlight the dialog within the data, which is not complete until moving into deeper interpretive analysis.

An example of this is shown below from Gwen’s Interview. The text in red are my interview questions, the blanked-out parts maintain the anonymity of the geographical location and the highlighted yellow is the text used to show the parts of the original transcript that were included when crafting the story. Words in [brackets] were added to join up the original text. Text was not only cut and pasted but reordered enabling the story to flow. The text below is shown as it was spoken. The nurse spoke of her experience of caring for this gentleman and other people at several points throughout the interview, but the experience is shown altogether, with her thoughts and feelings to create her crafted story.

5.2.1 Excerpt from Transcript of in-depth interview 7

Could you tell me about a time that you cared for somebody who was very breathless?

Have you got a particular person that you could recall?

Yeah. Yes.

We have. We've got a gentleman currently on our caseload.

He's my age, so young he's the same age as me, he is 51.

Alpha 1 Antitrypsin, his mother died, was also on our caseload and she died last year.

He has lived quite an alternative lifestyle, he's ignored his health really over decades and been a cigarette smoker. Heavy cannabis use, lives off the grid a bit. Sleeps in a workshop.

He does these amazing, very artistic, (with help now), sculptures that people commission

from him. I remember meeting him on a ward when I worked at the hospital in [REDACTED]

when he was an inpatient. Generally, DNA's follow up, doesn't want us to visit him at what's

his home address because it is a workshop and we've, I think, I persuaded him when I first

started in this role, and I saw him in one of the outpatient rooms at [REDACTED]. And

was concerned then, really, that he was limited and his FEV1 showed he is severe then and

he was still smoking but didn't want to engage and we have been writing to him probably

every two or three months since then. Saying we want to come and see you at home. The

GP writes to us and asked us to put oxygen in, but we're kind of saying we don't know that

he needs it and we need to go and see his home. Anyway, we finally got to see him.

I think due to the pandemic, he sees the lady that's our consultant lead. She is based at

[REDACTED] hospital but our [REDACTED] health board commissions clinics from [REDACTED]

hospital that she does. She has referred him for transplant assessment to [REDACTED] and

also to [REDACTED] for the valves. Endo bronchial Valve surgery and I think that's frightened him

and he's let us in now and we've seen him at home, and he can probably walk 10 metres

and he's lost weight. He can't bend down to pick anything up if he drops it because he's so breathless.

So, we've had in the last few months a lot more contact with him than we have had, we wanted that contact previously, but he hasn't engaged and I think yeah, I think it's fear, it's breathlessness. And it's hard because sometimes, we use the Cambridge breathlessness service leaflets. We like those so we decided not to redesign our own giving him all of the information. He's so breathless. I mean, I don't know if he'll even get to either of those assessments.

And probably our regular contact with him now is just to keep an eye on him and reassure him more than anything else. And it's really difficult because you can't. And I think he's probably aware, although he's never verbalised it, that actually a lot of what we're suggesting doesn't make much difference. And that we're going. We've got our health care support worker post, which is a new role we're developing, so we never send her to an initial visit. But she has a list of patients that actually you know she'll check inhaler techniques and go over some things, but actually it's some reassurance. So he's probably a good example, and is one of those visits that you dread 'cause you can't probably make much difference other than reminding that he hasn't been forgotten and that you are chasing the referrals and I don't know it's difficult, isn't it? He takes a lot of oramorph and I think he has given up smoking. I don't know if the oramorph has perhaps replaced the cannabis a little bit, I don't know, so he's probably an example of an unusual younger patient. I mean the other examples are a more end stage. Pulmonary fibrosis patients that we see, that's different, isn't it? Because they, if they're older and they have end of life planning? We work alongside the palliative nurses. It's different, isn't it? Because it's a different diagnosis and they're older, so it's just. In a way I don't say it's easy. It can be a smoother communication pathway. For them to accept, if that's the right word, intractable breathlessness and allow. Not allow it to happen, but live with that as it is knowing that it isn't ever going to be any different or better, whereas for this chap who lives in the workshop. I mean, I've said to you, if you have any

sort of surgery, this isn't the environment to recover from. He doesn't sleep in a bed, he sleeps on the sofa. It's not great. So that's very difficult.

Is that the sort of thing? That sort of example. Thinking he's probably the person that Springs to mind at the moment on our caseload.

What I'm interested in is how you feel in that situation. You know when you go in and you say "it's a slight dread", tell me about how that feels to be in that situation.

Right? I think you can feel quite helpless, and uncomfortable because actually, yeah, inadequate I suppose. Yeah, helpless in a way because there's nothing actually else that we can add in now that is going to make a difference to how his symptoms are. And it's really, it's uncomfortable to be there because we can only imagine can't we, what it's like to be that breathless. And he knows that, he knows that I don't know what that's like or any of our none of the team know. You know we whip in there, don't we all robust and he's there? I don't know. Yeah, I, you know it's horrible, isn't it? And I think I end up staying longer just chatting. And in a way, I hope that helps him, because he is shielded so he lives alone. So I am aware that I will stay and chat. And that's probably because we feel at a loss about what, there's not much more we can suggest, probably. Which is a very uncomfortable feeling, isn't it?

The highlighted parts of the transcript were then put together with some joining words to formulate Gwen's crafted story:

5.2.2 Excerpt from Gwen's Crafted Story:

We have got a gentleman currently on our caseload. He's my age, so young, he is 51. [He has] Alpha 1 Antitrypsin, his mother died [of the same condition], she was also on our caseload, and she died last year. He has lived quite an alternative lifestyle ignoring his health really over decades, he has been a cigarette smoker [as well as] heavy cannabis use, he lives off the grid a bit. He does these amazing, very artistic, sculptures that people commission from him, he has help with them now. He sleeps in a workshop. I remember

meeting him on a ward when I worked at the hospital in the {District Hospital} when he was an inpatient. The doctor has referred him for [a lung] transplant assessment and also for Endo bronchial Valve surgery and I think that's frightened him. He can probably walk 10 metres and he's lost weight. He can't bend down to pick anything up if he drops it because he's so breathless. We tried to contact him previously, but he hasn't engaged, and I think now [he's engaged because of] fear due to his breathlessness. He's let us in and we've seen him at home, And it's hard because sometimes, he's so breathless. I don't know if he'll even get to either of those assessments.

He's probably aware, although he's never verbalised it, that actually a lot of what we're suggesting doesn't make much difference. It is one of those visits that you dread 'cause you can't probably make much difference other than reminding him that he hasn't been forgotten and that you are chasing the referrals, it's difficult, isn't it? He takes a lot of oramorph, he has given up smoking. I don't know if the oramorph has perhaps replaced the cannabis a little bit. If you have any sort of surgery, this isn't the environment to recover in. He doesn't sleep in a bed; he sleeps on the sofa. It's not great. So that's very difficult and you can feel quite helpless, uncomfortable because actually, inadequate I suppose. Helpless in a way because there's nothing actually else that we can add in now that is going to make a difference to how his symptoms are. And it's really uncomfortable to be there because we can only imagine, can't we, what it's like to be that breathless? And he knows that I, or any of our team don't know what that's like. We whip in there, all robust and he's there. It's horrible. And I am aware that I will stay longer just chatting in a way and that's probably because we feel at a loss about what [to do], there's not much more we can suggest which is a very uncomfortable feeling, isn't it? I hope that helps him, because he is shielded so he lives alone. I don't know what'll happen to him.

This excerpt demonstrates how the dialogue flows as a story, honouring much of the original narrative but framing it to read fluently to describe less of what was done and more how it felt for Gwen.

Following the crafting this story, I wrote this in my reflexive diary:

5.2.3 Reflexive diary extract June 20th 2022

This nurse used a lot of emotive adjectives such as 'harrowing', 'sits heavy', 'horrible' and 'distressing' to describe the discomfort of supporting a patient with chronic refractory breathlessness. While this was honest and reflective when asked how this experience affected her personally and professionally, she was very clear to say that this only affected her professionally because she enjoyed her job. I cannot see how there can be such a clear distinction between professional and personal distress/challenge. Several times she referred to the prospect of leaving respiratory nursing because of the challenge but each time said she would not.

Is it because to admit something has personally challenged you is to change the expectations; we have of ourselves in our role? To somehow feel personally challenged is to admit that professional boundaries have not been maintained, yet exploring the blurring between personal and professional so often means that what we bring to a job we takeaway in our personal lives. I would certainly have probed deeper with her about this if it had struck me at the time of interviewing as it does now, so I can only surmise at what was behind this comment.

It does make me question whether admitting something has personally affected you is to have failed and as a team leader with many years of clinical experience this is not a narrative that she would consider. In fact, to admit personal challenge is to acknowledge the enormity of the role and responsibility, its complexity and the personal integrity that goes into caring for people with chronic refractory breathlessness.

5.3 Crafted story as a means of analysis

Crafting Gwen's story from the transcript was a way of being in relation with the data, crystallising the essence of her experience of supporting people with breathlessness into a narrative. Many of the nurses wanted to describe what they did more than how they felt which meant there was often a to-and-fro in questioning before they shared their feelings. Several nurses struggled to engage in this way at all, probably because the CRNS role requires a focus on the ontic rather than the experience (ontological). My own reflexive account highlights my thoughts about how the experience of breathlessness, evoking personal thoughts and feelings that might not sit comfortably for Gwen in a professional role as a nurse team leader but are nonetheless part of the human experience of engaging with another with breathlessness.

A further five of the crafted stories are presented in entirety in appendix 9. Each story, annotated with comments to demonstrate the ongoing analytical process, is followed by a commentary where Heideggerian notions were identified and my reflexive diary accounts. The criteria for inclusion of these five stories was based on the stories that were most frequently referred to in part 2 and 3 of the analysis.

5.4 Conclusion

This brief chapter has outlined for the reader an example of an interview transcript being transformed into a crafted story. The process reveals how the data is not changed, but moved around to enable flow of the story, framed through experience, being told. In the next chapter, stage 2 and 3 of the analysis reveal how, following this process of crafting stories, Heideggerian notions revealed a deeper understanding from the participants experiences which led onto unconcealment of the phenomenon through attunement.

Chapter 6 Analysis: Part 2 and 3

“Research is seeing what everybody else has seen
and thinking what nobody else has thought.”

Albert Szent-Györgyi

6.1 Introduction

Having outlined the process of crafting stories in chapter 5, I move on to outline the use of Heideggerian notions read alongside each crafted story as part 2 of the analysis. I describe how these notions are revealed through the crafted stories, deepening understanding of the participants' lived experiences. In part 3 of the analysis, I describe how, through attunement, the phenomenon of fulfilment was revealed, through the crafted stories identifying components of this phenomenon revealed through Fulfilment-as. Through these 3 stages of analysis the complexity of the experience of care is revealed bringing new understanding to the perception of bearing witness to the distress of breathlessness.

6.2 Second stage of analysis: Heideggerian notions

Having read extensively around Heidegger's philosophy, I wanted to use his notions as an analytical framework to demonstrate understanding and elicit meaning from my data. This use of Heidegger's existential structure is not always evident in phenomenological research (Gullick and West, 2019) but its use demonstrates how Heidegger's philosophy can illustrate concealed elements of lived experience. Through the crafted stories, the use of Heideggerian notions is a way to show what is seen and heard, signalling to the reader where further discussion and thinking might occur. The notions, or existentials that showed themselves in this study were primarily *leaping-in/leaping-ahead as solicitude, thrownness,*

being-toward-death and *the state of the uncanny*. I will also briefly explore *being-with* and *machination*.

Following each crafted story, I wrote a commentary considering the Heideggerian notions that presented themselves in each story (5 of which are shared in full in appendix 9). In exploring each notion, I present excerpts from these commentaries, as well as my reflections to show my presence in the stories, exploring what this might reveal from the data. This is summarised in table 1. Each notion will be explored in relation to the participants' experiences and examples from the crafted stories will demonstrate how use of the notions reveal a deeper understanding.

Table 7 Summary of Stage 2 of Analysis

Heideggerian Notion	What this reveal from the data
Leaping-in and Leaping-ahead as solicitude	Identifies how care is delivered by each CRNS, journeying with their patients, and facilitating rather than doing-to
Thrownness	Individuality and uniqueness of each nurse (gender, historicity, culture, age etc) is borne out in their experience of care
Being-toward-death	Participants witness of suffering through breathlessness confronts them with possible death, but unlike other research

	papers: participants remain present with their patients
The state of the uncanny	Breathlessness is unsettling and uncomfortable for CRNSs despite their professional experience and expertise
Machination	The discomfort of witnessing breathlessness leads some CRNSs to focus more on the implementation of technology, this is “doing” rather than “being” which feels vulnerable
Being-with	Being-with someone who is breathless is challenging, leaving nurses feeling exposed at not being able to change outcomes yet they remain present and find meaning in this experience. This reveals the phenomenon of fulfilment.

6.2.1 Solitude as leaping in/leaping ahead

Only if care is dasein and dasein is care, its significance in the world can be demonstrated (Inwood 1997). The concept of "care" surpasses the temporal aspect of dasein (human existence) and extends to dasein's coexistence with entities in the world. Heidegger refers to care as caring or worrying and taking care of things. Solitude (fursorge) refers to care for

others in relation to oneself, not as altruistic as care in nursing would suggest. However, solicitude will be referred to as nursing care in this study demonstrated by leaping in and leaping ahead.

Leaping in/ leaping ahead is described by Heidegger as "that which leaps in and dominates, and that which leaps forth and liberates" (1962 p158). Leaping-in defines being-with in relation to immediate, situated concerns that take over from the "Other" (in this case 'the patient') (Heidegger, 1962). It is associated with disempowerment although relevant when a person's needs are acute and need to be proactively managed. When leaping-ahead Heidegger sees this as being ahead of the other not to remove care but to give it back, helped by the underlying relationship between nurse and patient enabling a mutual trust. Leaping ahead is especially congruent with community care because we enable, facilitating self-management and empowering people in their own homes. Through this fluctuation, dasein can both care for and care about the other.

Esther identifies that care as leaping-ahead for people with breathlessness is challenging:

"...but he is frustrating and when I first went, I wanted to sort them out. And I couldn't. I think it was that thing: right if we just do this, and he didn't. There was a phase where I really did want to chuck long term [oxygen therapy] all of that at him, I'm still sometimes a secondary care nurse of "Do, treat, do do".

Crafted Story for Esther, Int 5

For Esther, 'sorting them out' was leaping in which Esther resisted. Leaping in was instinctive for Esther from her acute care experience, but she recognised this was not the way in community nursing.

Leaping-ahead can be challenging as Gwen demonstrates, revealing the cost to her in taking this path:

He's probably aware, although he's never verbalised it, that actually a lot of what we're suggesting doesn't make much difference. It is one of those visits that you dread 'cause you can't probably make much difference other than reminding him that he hasn't been forgotten and that you are chasing the referrals, it's difficult, isn't it? you can feel quite helpless, uncomfortable because actually, inadequate I suppose. Helpless in a way because there's nothing actually else that we can add in now that is going to make a difference to how his symptoms are. And it's really uncomfortable to be there because we can only imagine, can't we, what it's like to be that breathless?

Crafted story, Gwen

This desire to "do" would be a diversion from witnessing suffering and death for both patient and nurse but there is nothing more to be done. Therefore, in choosing to visit this gentleman she faces this with him, staying to chat leaves her feeling vulnerable and uncomfortable. For Gwen, this choice of solicitude as leaping ahead is a cost to her, in putting her patient's needs beyond her own desire to spare herself from this vulnerability, focused on care that is "harrowing".

Commentary for Gwen

Leaping-ahead led Hilary to question their effectiveness as a nurse, questioning themselves and undermining self confidence in the role.

And so you do just sort of feel like gosh; you're racking your brain almost. What else can I do? There must be something that I can do, I think as a nurse your whole ethos is about relief of suffering. You want to make people feel better and when you're faced with a situation where you can't make it better, that's really difficult and it's not a comfortable feeling to feel helpless and like there isn't anything I can do to make this situation better. When reflecting back [I think] am I doing enough? Is there something else that I should be doing? And that makes you feel quite critical of yourself when you're faced with a situation like that that is so challenging that you want to be able to do something even when there isn't necessarily something that you can do to make it better.

Crafted story, Hilary

Witnessing this man's predicament is personally and professionally challenging for Hillary both in being alongside his distress and in seemingly falling short of their expectation of what it means to be a nurse. Their expectation of themselves that as a nurse they will relieve suffering, which is confronted when, despite every practical intervention this man's breathlessness persists and his suffering is clearly not relieved.

For Hillary, this understanding of what it means to be a nurse comes from their subjective experiences shaping their cultural, social, historical and political perspective to arrive at this perspective. Their dasein is shaped by this and will shape their encounters with others. This desire to leap-in to assist would meet Hillary's need to fulfil their role as they see it but there is nothing that can be done. Hillary does recognise the skill of a nurse is to develop a therapeutic relationship with patients. However, while they recognise a connection is made with their patients by sitting and listening, acknowledging their concerns, they do not feel they have "done anything", despite the patient saying they feel better. In drawing alongside their patients, Hillary is actually leaping-ahead authentically releasing solicitude. Enabling their patients to stand on their own 2 feet and processing their thoughts and feelings, Hillary is reducing their dependency giving back care to themselves.

Commentary on Crafted story Hillary

The notion of leaping-ahead shows the impact of meaningful engagement between nurse and patient, exposing the personal cost to them. Their fundamental ontology, revealed through relationship and bearing witness to breathlessness, is shaped by their thrownness.

6.2.2 Thrownness (taken for granted situatedness in our environments)

Dasein is already-in-the-world, aware of its past, present and future. This facticity: the fact that dasein is 'always already' with mood or state of mind reveals its thrownness (Inwood 1997). Thrownness demonstrates temporality and historicity for each nurse, impacted by the culture of the organisation, the home dynamics shaping the attunement, interpretation and

understanding of their experience beyond the ontic practicalities to their ontological experience. Thrownness is thus revealed showing each nurse's situatedness, bringing a unique encounter between each nurse and patient.

For Esther, thrownness is explored from her experience of critical care coming into community respiratory nursing. Her approach to clinical practice to this point has been shaped by measurable interventions that are the bedrock of critical care, so coming into the community from the acute sector is framed entirely by her previous experience:

Moving into the Community is that strange thing where consent and the privilege of being in somebody's home mean relationships are very different to being in critical care. [In critical care] there are a lot of assumptions about best treatment and that sort of thing, so it was quite difficult, and it took me at least two or three years to settle into the job. I found a lot of the time I felt "I'm not doing anything". The work, the pace of the work and how you measure it is very different.

Crafted story Esther

Esther frames her story within her long career, predominantly as a critical care nurse. She recognises that over 30 years in critical care of personal and professional experiences informs her professional identity and current practice in community nursing. For Esther Dasein, that is, being in the world is informed by the totality of her experience including her position today. Her lifeworld is intrinsically shaped by temporality engaging the past, present and future of dasein. Dasein connects us to the world just as we impact the world. This is evident for Esther as she navigates her situatedness in community nursing from the personal experiences and prejudgements of a critical care nurse which has shaped her professional identity. For Esther, coming to community respiratory nursing that she identifies as quite different to critical care, she feels a dissonance that reflects in her attunement.

Commentary, Esther

Esther's account contrasts with Carrie's who brings herself very much to the clinical encounter:

We are not made of stone and often we know these patients, sometimes for years and are very involved so when they are struggling with symptoms it can be like watching a loved one. I do think about it outside work and there's a sadness and a grief, especially when they die.

Crafted Story Carrie

Carrie cares deeply for her patients expressed by how she thinks, feels, acts and works. In this way the thoughts she shares regarding her experience of supporting patients with breathlessness go beyond her clinical role as a CRNS in sharing her own feelings. This attunement, how she finds herself is demonstrated as she describes the personal impact of care, the costs of it but also the rewards of feeling connection with her patients. Carrie's thrownness as a CRNS is conflicted between how she carries out the role and how she perceives others consider how nurses should be when she mourns her patients. Carrie does not differentiate her professional position of care from her personal feelings for her patients yet is conscious that some might consider she should not have this emotional connection in her work.

Commentary Carrie

In witnessing the distress of breathlessness, thrownness shows that Andrea (Int 1) is immersed in the clinical encounter, beyond the ontic to an existential encounter which resonates with my own experience:

She feels their pain which is deeply uncomfortable as she has a personal desire in her to make things better and is distressed when she cannot do this. She is at the point with this lady that no amount of doing (equipment/practical things) will help take the indignity of breathlessness away, it is in being-with, witnessing the distress and continuing to visit (she could refer on to palliative care and discharge her from her caseload) that demonstrates her humanity but causes her pain. This story resonates with me, and I can relate to this feeling that somehow just showing up is not enough, it will never be enough. Our heads tell us that is how it must be but our hearts tell us it is not enough. We see our roles as nurses "to fix" and feel impotent and exposed when this is no longer a possibility. All we are left with is

witnessing the patient's distress which challenges us to step out of the boundaries of clinical practice and into a human-to-human experience, to dare to consider what it feels like to experience such discomfort, fear and disability.

Reflexive diary entry following interview 1

Andrea's thrownness, and my own thrownness give us angst within our nursing roles and from a personal perspective. Our nurse training is predominantly focused to 'do' rather than 'to-be'. This does not mean we fall short, but we find ourselves challenged, impacting how we find ourselves. For dasein, the ultimate challenge is authenticity in the face of death, looking forward to its death as well as back to its birth and beyond birth to its historical past (Inwood, 1997).

Fiona articulated her situatedness as a woman, mother, wife and nurse and was conscious of these competing roles impacting her patient encounters. The longevity of experience revealed that she recognised her perspective has changed over time and she is now more aware of the personal impact of her professional role.

6.2.3 Being-toward-death

Biological dysfunction allows us to come to terms with the frailty of the human condition (Aho 2014), seen in this study through people with breathlessness due to respiratory disease.

Phenomenology helps us understand our ontological relationship to death rather than analysing the ontic, physiological process of death (Carel 2013). The CRNSs in the study recognized that in bearing witness to breathlessness, for many of their patients, the severity of their condition and degree of breathlessness signalled they were nearing death. For Heidegger, in being-toward-death we are paying attention to our human condition and the certainty of mortality. The concept of time and temporality is integrated with meaningful existence with being-toward-death because we are living a life wrapped up in the past but

aware of our future ending and our mortality (Dibley et al., 2020). Mortality is one of the few certainties in life so recognising that human life is 'on the way' and always uncertain, time is wrapped up in what it means to be human (Dibley et al., 2020). Heidegger argued that dying is a phenomenon that needs to be understood existentially, distinguishing between physically perishing and dying. Perishing is an extinction of biological life (Gullick and West, 2019) in contrast to dying which is understood existentially by dasein's positioning toward "no-longer-being-able-to-be-there" (Heidegger, 1962, p251). Only when Dasein has grasped the finitude of existence can it be brought back from the infinite multiplicity of its possible ends to the simplicity of its fate (Heidegger, 1962, p384).

Gullick and West (2019) identify in their meta-synthesis on being-toward-death that all the nurse participants in the papers were uncomfortable being alongside death, including talking about dying. They dealt with this by being busy caught up in the mundaneness of the 'they', ensuring patients were physically comfortable rather than being emotionally available. The studies included by Gullick and West (2019) all involve nurses working in inpatient settings. This study is focused on the work of community nurses where clinical encounters in the patient's homes are often more private, less time pressured and often more intimate due to the longer-term nature of the relationship than hospital. This study data shows that participants did come alongside their patients toward-death, and shared their discomfort in doing so, as reflected in Andrea's story:

What drives me is I can put myself in the patient's position: I can see the terror in their eyes and imagine how that feels. What is more frightening than thinking you are going to die gasping for breath? Many of our patients live with this daily and are terrified. Nobody should suffer like that...She has the most severe breathlessness I have witnessed. I don't know how she manages, caring for her breaks my heart. I have worked hard to make sure she has everything, but I can't do anything else. I have felt really upset at times knowing that she gasps for breath just to have a wee. Nobody should suffer like that; it really hurts me to see her suffer like she does.

Crafted story Andrea

Andrea can put herself in her patient's position and can see the burden of living with breathlessness. She recognises that these ongoing experiences of breathlessness bring terror and fear of death, an existential fear that cannot be denied when breathlessness permeates every aspect of her patient's lives. Heidegger speaks of in being-toward-death if we are to live authentically. This fear of death, explicitly demonstrated in severe breathlessness cannot be denied by patients and their families, or by Andrea.

Andrea recognises these symptoms are particularly severe, the worst she has witnessed. She has seen many people with breathlessness in her career of 27 years and has an idea of what to expect for patients with respiratory illness. Her expectation of symptom burden is challenged by this lady's experience which leaves her unsettled, exposing her expectations of herself when caring for this lady. In witnessing this lady's symptoms Andrea has her own existential awareness of the depths of human suffering and indignity. She is distressed to see this suffering and to feel that she cannot do anything to relieve the suffering. Witnessing this suffering hurts her personally, beyond her nursing role.

Commentary on Crafted Story Andrea

For Andrea witnessing her patients' breathlessness represents the patient's certain death through respiratory illness. Andrea's close involvement with this lady's care and empathy for her suffering expose her personally to the possibility of being-toward-death which she witnesses practically in the lady's body physically perishing and existentially in her dying. Andrea does not retreat beyond her nursing role as the nurses appeared to in Gullick and West's meta-synthesis (2019). She faces this reality, exposed to vulnerability and self-doubt yet steadfast in her commitment to care. This is echoed in Hilary's account where they are confronted by the distressing reality of a dying patient but remains focused on the task in hand:

And, and what particularly struck me when I saw him last week was that as we were drawing things to a close and I was getting ready to leave, he said, "do you know: I'd just like one

day, where I can breathe. That's all I want, just one day". And I thought gosh, how dreadful to feel like every day is an absolute struggle for you.

Crafted story, Hilary

Witnessing this man's predicament is personally and professionally challenging for Hilary both in being alongside his distress and in seemingly falling short of their expectation of what it means to be a nurse. Their expectation of themselves that as a nurse they will relieve suffering is confronted when, despite every practical intervention this man's breathlessness persists and his suffering is clearly not relieved. This leaves exposure for Hilary to be-toward-death with their patient and a feeling of helplessness and self-criticism. Such is this allocentric desire that rather than retreat, Hilary is spurred on to do their best for their patient.

Commentary on Crafted story Hilary

Both participants' accounts show their commitment to bearing witness to their patient's distress, challenged by the emotional labour required of them yet are resolute in their focus. Gwen too is confronted by being-toward-death:

It's horrible. And I am aware that I will stay longer just chatting in a way and that's probably because we feel at a loss about what [to do], there's not much more we can suggest which is a very uncomfortable feeling, isn't it? I hope that helps him, because he is shielded so he lives alone. I don't know what'll happen to him.

Crafted story Gwen

[The patient] has seen his mother die of the same illness very recently and he can no longer ignore that he is toward-death. He is fearful and only allows the nurses to visit him at this point. His thrownness and the prospect of his future sit heavily for Gwen, witnessing his distress with severe breathlessness and all this projects for the future. His being-toward-death means she too is confronted by being-with-death.

Commentary on crafted story, Gwen

6.2.4 State of the uncanny

This notion spoke to me through the crafted stories and commentaries in portraying the participants' sense of angst and discomfort when attuning to the interview data. The experience of supporting people with breathlessness has shown itself to be challenging and unsettling, exacerbated within the context of a global pandemic. The context of when these interviews were recorded between Dec 2020 and July 2021, a time when the whole world felt unsettled is undoubtedly reflected in the accounts of participants. As Aho, (2020) described, the pandemic was not only unsettling personally, but for healthcare providers it put overwhelming demand on services. The anxiety and *not-at-homeness* resulting from disruption to work life by working remotely, getting used to wearing PPE (personal protective equipment) and for some: shielding heightened the participants feelings of being unsettled.

All the CRNSs alluded to the global COVID pandemic as having a personal and professional impact. Janet (Int 10) identified that COVID has highlighted issues in the service that were already there:

We've been struggling 'cause we've had no staff 'cause we've had no management and other people have been off sick and we still managed to maintain services. Covid's made it worse.

Crafted story Janet

Janets' angst was particularly explicit due to the pandemic, she was the only CRNS not to share her love of the job, focusing more on her current disillusionment and frustration. In many ways I was surprised that Janet was the only nurse to be so vocal about her frustration given the upheaval and challenge of the pandemic. For Carrie, having to shield during the pandemic highlighted how this had impacted her ability to support her patients how she wanted, leaving her with angst:

I feel like perhaps I could have done better by visiting more and being there, but it was in March [2020] when Covid started, and we couldn't do that. Other people [in the team] had to

visit my patients [because I was shielding] so I couldn't actually do any visits, [it made me feel] a little bit of a failure, there was almost a feeling it was unfinished.

Crafted story Carrie

Carrie's focus is back on herself, unlike Janet who is frustrated with the injustice of excessive workloads and understaffing.

Irene identifies that supporting people with breathlessness has always been challenging because there are few easy fixes. This may feel especially hard for a nurse like Irene who, in her senior role, is used to finding solutions and making effective pathways of care:

I think I've always felt inadequate with the expectation when I go out with the community matrons, and I think their expectation is that I'll come up with some kind of miraculous new concept that we can do and I don't have anything up my sleeve. I haven't got anything. I can't wave a wand and make it OK.

Crafted story, Irene

The reality of being faced with someone who is profoundly limited by breathlessness is unsettling as Gwen describes:

It is one of those visits that you dread 'cause you can't probably make much difference [It's] very difficult and you can feel quite helpless, uncomfortable because actually, inadequate I suppose. Helpless in a way because there's nothing actually else that we can add in now that is going to make a difference to how his symptoms are

Crafted story Gwen

Whilst Gwen acknowledged there is no more practical intervention to be done, she personalised and internalised this lack of action to personally feel unease and angst when

reflecting on this patient experience. Esther identifies how the experience of witnessing breathlessness is made more challenging by her initial unfamiliarity with community nursing:

I can remember the first time I had experiences like this, I felt completely lost and unsupported. I used to really feel I haven't done anything; I haven't helped him that's how I felt, and I also felt a bit cheated because I was going to do ambulatory oxygen assessment which should have been just a quick walk around the garden and it wasn't. When you work in a secondary care environment, you can go hah! you can go in and say what's going on? [In the community] I don't know what to do, I'm not sure if I've done the right thing and I always find when I walk away from patients' home, and I feel unsettled, I felt I was leaving something undone and I found that very hard.

Crafted story for Esther

This uncanny, angst feeling is also personalised by Esther, aware that she finds it easier and is more comfortable with the “do, treat, do” approach than being open to the possibility of ‘being’ rather than ‘doing for’. While this unsettling for Esther, she reflects throughout her story that she has found strategies that help her when working in the community: of managing her own expectations (“I am not the saviour”), of asking her colleagues for advice and of learning about the culture of the organisation. Heidegger suggested that through the discomfort the state of the uncanny brings, there can be an opportunity for transformation by being open to possibilities. These are hidden when we remain in our comfortable, home-like state. This opportunity for transformation is confirmed by Hilary and Carrie, who both acknowledged how the unease of supporting people with breathlessness has helped spur them on and recognise their own experience and determination to provide ongoing support.

And that makes you feel quite critical of yourself when you're faced with a situation like that that is so challenging that you want to be able to do something even when there isn't necessarily something that you can do to make it better. I suppose it's that what spurs you

on to keep going and to help your patients as much as you can and think, what I am doing is valuable and I want to do the best that I can.

Crafted story Hilary

I think there's always that sense of unease, while you're waiting for things to settle and hoping that they'll settle. And I think if it's more of an ongoing, intractable breathlessness there's just a feeling that I hope I can help this person. But through experience, knowing that sometimes I can't help as much as I'd like to. And If you can't do that, there's trying to find ways of supporting them through it, that's also a level of determination to try and see that through.

Crafted story Carrie

The determination described by Hilary and Carrie enable them to reflect on how they can support their patients, including through the use of technology.

6.2.5 Machination

Heidegger referred to the adoption of technology in our lives as machination. It is not the technology he objected to but our relationship with it, removing us from engaging with each other. This is increasingly recognised in all areas of nursing as it becomes task orientated and technical. It can be a particular issue in specialist nursing such as respiratory where there is a focus on inhalers, oxygen equipment, clinical observations and investigations (spirometry, peak flow metres etc). The notions explored have demonstrated the challenge of supporting people with breathlessness where there are few fixes, exposing nurses to feelings of vulnerability and unease. This is demonstrated by Belinda:

So first of all I sorted out getting referrals into other services. It felt important to get the district nursing team on board. I got him a profiling bed to help with his breathlessness so he could sleep more upright....I got him a high flow concentrator so he could mobilise around his bungalow on the appropriate level of oxygen.

Crafted story, Belinda

Belinda's thrownness leads her to focus on machination for her patient, a means of leaping in to keep busy with legitimate things. She will arrange equipment to deliver high flow oxygen, arrange a profiling bed and refer to colleagues. Belinda is leaping-in, using her knowledge and experience in anticipation to ensure her patient's needs are met, relieving him of these concerns. Belinda's approach through dasein of machination is a way of removing herself from the authenticity of being toward death.

Commentary Belinda

Belinda's desire to offer practical support, as well as speaking in the third person: *"you have done what you should have done and done a good job"* removed herself from the experience of her patient of suffering and death. Heidegger spoke of being toward death and facing death as bringing the possibility of living an authentic life, yet this process is generally suppressed in society owing to the anxiety that facing death causes death to be interpreted on a personal level as "death not yet".

Hilary reflected how once all the equipment and intervention are in place, the breathless person's 'being' is no longer concealed or hidden, exposing them to feeling helpless and uncomfortable at not being able to fix the situation.

[It makes me feel] a bit hopeless and helpless really; sorry. He's on maximal therapy and medically there's nowhere else that we can go, he is using things like fan therapy, breathlessness management techniques, he's done pulmonary rehab previously, done the breathlessness management course at the hospice previously.

And so you just sort of feel like 'Gosh!' you're racking your brain almost. What else can I do? There must be something that I can do, I think as a nurse your whole ethos is about relief of suffering. You want to make people feel better and when you're faced with a situation where you can't make it better, that's really difficult and it's not a comfortable feeling to feel helpless and like there isn't anything I can do to make this situation better.

Crafted story, Hilary

Hilary was exposed to being-with their patient, something that this study demonstrates is incredibly hard for the CRNSs who took part.

6.2.6 Being-with

Dasein refers to being-in-the-world, an ontological experience that is understood through experience. Being-with, translated from German 'mitsein' (sein- to-be, mit- with) is dasein-with, so being with one another (Inwood, 1997). Heidegger referred to this as presencing and letting-be-present (1971). The concept of presence is integral in nursing when bearing witness to the distress of breathlessness (Speakman, Butcher and Schutz., 2021a). It is difficult to achieve in busy environments dominated by the biomedical model (Djkowich *et al.*, 2019) but is possible through "genuine human-to-human relating" (Cody, 2001, p290). The CRNSs in the study share their experiences of presence with their breathless patients, demonstrating genuine engagement but at quite a personal cost as Andrea described:

I ask why can't I do more to take the suffering away? I feel caring for her is humbling and sometimes I feel I am failing her. I have worked hard to make sure she has everything, but I can't do anything else. I have felt really upset at times knowing that she gasps for breath just to have a wee.

Crafted story Andrea

In witnessing this lady's symptoms Andrea has her own existential awareness of the depths of human suffering and indignity. She is distressed to see this suffering and to feel that she cannot do anything to relieve the suffering. Witnessing this suffering hurts her personally, beyond her nursing role. Andrea's witness enables her to leap ahead in her solicitude.

Commentary Andrea

Fiona also felt the burden of witnessing the distress of her patients with breathlessness:

I certainly can't say that 5:00 o'clock or whatever time, I don't just shut off, it's very hard to shut off when you're working with people like this. I do think about people or dream about all of these things. I think personally it does affect your life and I think I might not necessarily be aware of it but I've become more aware of it over the years. But you know, if you have these intense experiences with people in the day, often you don't have anything left to offer at the end of the day, to your family or friends. I've got young children and you have to do it, but I think sometimes you haven't got a lot left to offer people, so I think it takes up a lot of energy and a lot of your sort of mental and spiritual energy as well. All those things that you invest, and you give so much, and people take quite a lot as well so you know you are giving so much of yourself that sometimes it comes to the end and you think I haven't got anymore. You know, that's it for today.

Crafted story, Fiona

While she visits her patients in a professional capacity, she brings herself personally to the role as a respiratory nurse specialist, and as a result describes the personal challenges resulting from professional encounters. This temporality, informed by the longevity of experience reveals her perspective has changed over time and she is now more aware of the personal impact of her professional role. Her situatedness in the world is shown by her engagement, her understanding of being needed and valued by her patients and the responsibility she feels from this. This responsibility sits heavily with Fiona because she is so passionate about her work, she strives to do the best for her patients.

Commentary Fiona

Being-with is challenging for these nurses yet they share a determination to do the best for their patients, echoed by all the CRNSs in the study. Their drive and determination is the focus of the third stage of analysis, where the phenomenon of fulfilment revealed itself.

6.2.7 The notion of fixing

The goal of nursing has traditionally been seen as disease prevention and health promotion with the central phenomena of care and caring (Euswas and Chick, 1999). Nurses assess and identify patients' problems in order to plan for interventions that will alleviate or "fix" these problems. The nurse works in collaboration with the person but is ultimately considered (by themselves and others) as responsible for fixing problems. One of the difficulties in having responsibility for "fixing" problems is that in many fields of nursing there are problems that cannot be fixed (Bennett, 1992).

The desire to "fix" is hardwired in many nurses so when this cannot be achieved it can lead to feelings of inadequacy and perceived failure when the symptom, such as breathlessness persists. In fixing or alleviating problems, nurses can avoid their own existential crisis of being-toward death by witnessing suffering, avoiding vulnerability and discomfort. The alternative to "fixing" is 'being-there' and can be superficially perceived as doing nothing.

Cicely Saunders (1918-2005) was one of the first to coin the phrase 'being-with' in nursing. The founder of the modern hospice movement, Saunders was driven by her witness of nurses in the second world war, caring for soldiers who, faced with drug and equipment shortages, had little to give but themselves when caring for the dying (Saunders, 1976). Saunders model of care puts 'being-with' at the heart of end-of-life care and far from doing nothing, recognised this meaningful engagement was a profound gift to patients. This is by no means easy for nurses (Speakman, 2018), as the present study participants revealed when recounting their experiences because it is not tangible or quantifiable. "Being-with" is valued by patients (Arman, 2007, Fahlberg and Rousch, 2016) yet well recognised as a challenging aspect of clinical practice (Paterson and Zderad, 1976, Haraldsdottir, 2011). The NMC code of conduct (ref) identifies good practice by putting safety and effectiveness of patients and service users first, promoting trust through professionalism. Competing

pressures, limited resources and an ageing population makes creating a culture in which “being-with” is challenging and the traditional intervention of “fixing” is preferable (Bennett, 1992).

This dilemma for fixing versus being with was prevalent throughout the present study for participants. Hilary identifies the discomfort they felt:

“... when you're faced with a situation when you can't make it better, that's really difficult and it's not a comfortable feeling”

This is explored in detail through the Heideggerian notions (6.2) revealing further examples of the challenge “being-with” presented to the participants.

Yet analysis revealed, through the phenomenon of fulfilment (6.3) that being-with was profound for participants, they recognised its importance and many of the quotes demonstrate their understanding of this, including Irene's reflection that:

“...I acknowledge that and I hear you and you know I am here for you”

The present study therefore revealed that although for many of the participants “fixing” felt preferable, they recognised when supporting people with chronic illness this was rarely achievable. Their engagement and commitment to their patients enabled them to appreciate the importance of them “being with” those they cared for, even though it remained a challenging aspect of care.

6.3 The Third stage of Analysis: revealing the phenomenon through attunement

The third stage of analysis involved reflecting on the videos of interviews, stories and commentaries; attuning to the interviews, which revealed the concept of fulfilment. Although fulfilment is not directly referred to by any of the participants, there was an attunement evident in every interview. That is not to say this was the only attunement, but it was one that resonates across the twelve interviews.

In Interview 5 Esther's mood was deeply reflective and sometimes frustrated, a frustration borne out by her thrownness as a critical nurse in a community role that differs with Janet (interview 10) for whom there is a mood of frustration she links directly with the current COVID crisis. In interview 6 there was a mood of exhaustion that Fiona describes as low-level grief, considering the work of caring for respiratory patients at end of life, the current global pandemic and isolation that brings to the role due to working remotely. Interview 11 had a definite mood of cheerful positivity, at the point of retirement Katy looked at her patient group and her own skill set with acceptance and positivity that she recognises has come with age and experience.

In considering the attunement of the interviews I reveal how the components of the ontic and ontological shape the experience of being a CRNS caring for their patients with breathlessness.

6.3.1 Illuminating the phenomenon

The phenomenon of fulfilment revealed itself to me following stage two of analysis when I explored the data with the philosophical notions. Heidegger (1962) described attunement as mood (*stimmung*) or '*Befindlichkeit*', translated as how one finds oneself. We are always in a mood and need to have openness to possibilities for these to resonate. For example, to find something threatening, one must be open to the possibility of threat. As the researcher paying attention to the attunement present in the interviews, I had to be open to the possibility of fulfilment for this to be seen. I recognise that my own position as a nurse and

researcher will have contributed to this attunement and feel this should be acknowledged. I am aware it is through my own lens on clinical practice and philosophical understanding this phenomenon is seen. My orientation might differ from another for whom this phenomenon might be absent, and another phenomenon might be revealed. For myself as a CRNS and researcher, in dwelling with the data once this phenomenon was unconcealed and once seen, could not be unseen. However, I demonstrate, with examples from the crafted stories, that this is indeed a phenomenon that can be seen in the data. I will explain how extensive reading, and then re-reading around the subject and dwelling with the data led me to the possibility of fulfilment as a phenomenon.

Returning to the literature around witnessing distress, being-towards-death and emotional labour, I did not feel that the conclusion that this inevitably leads to burnout and trauma made by many authors adequately represented the conversations and picture of experience described by my participants. I was looking for balance in the literature of exploring emotional labour but also job satisfaction and this rarely came. Literature regarding emotional labour seemed to be either focusing on how this can lead to fulfilment in nursing (Perry, 2002, 2007 and 2008 talks at length of the fulfilment of being a nurse) or connect emotional labour with burnout and poor care (Smith, 1992, Sorensen and Iedema 2009, and Sawbridge and Hewison, 2013). Looking back to the crafted stories it seemed that nearly every participant ended with a sense of positivity, having started the conversation talking about their love of respiratory nursing; they finished mentioning this as well. This was despite their grief, distress and challenge in caring for their people with breathlessness, speaking of complexity of emotions; a reward and satisfaction, and a comfort they felt in their role. I understood that it was the attunement of the stories that was speaking to me. The attunement of each interview showed fulfilment as the phenomenon and although nobody actually said, 'I am fulfilled' (Andrea spoke of feeling valued and Deborah talked a lot about job satisfaction), once recognised, this phenomenon was very present in each story. However, I did not want to represent the stories just to be about fulfilment in a clear-cut

binary way of negative or positive because there is a complexity to dasein, to the thrownness and fallenness for each participant. Participants also spoke of their grief, pain and discomfort through their experiences, so exploring and representing complexity was important.

Therefore, the idea of *fulfilment-as* enabled a more detailed opportunity to explore the phenomenon in the stories and to represent the antonym of fulfilment as burden/cost and frustration for participants where this was represented too.

My reflexive diary acknowledges my thoughts as the phenomenon of fulfilment revealed itself to me:

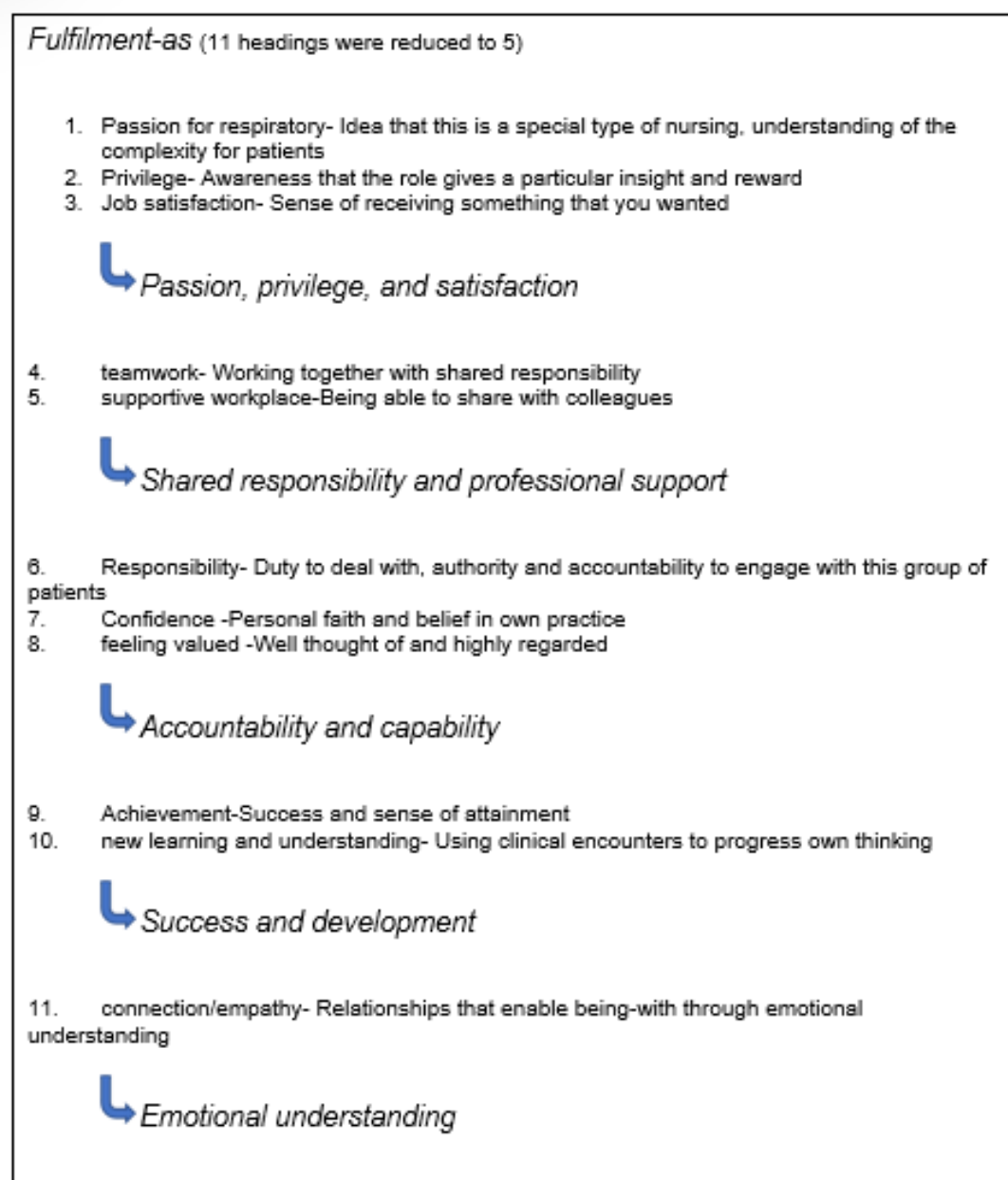
Aug 9th, 2022: The phenomenon of fulfilment revealed itself to me when I explored the data with the philosophical notions. The literature around emotional labour and distress connects with burnout and trauma and does not represent the conversations I have had with my participants. There is a feeling of positivity resonating from every interview. They nearly all start and finish the interviews talking about their love of respiratory despite the grief and distress they share. I did not expect to be discussing fulfilment but now I am aware of it, can see it in the data everywhere

Each participant shared candidly their experiences of caring for people with breathlessness, recounting feelings of inadequacy, discomfort and challenge. But they all, without exception, also talked about their love of respiratory nursing and their connection with the care they give. The revelation of pain and distress through the Heideggerian notions and then phenomenon of *fulfilment through attunement* demonstrates that for the participants this care evokes dialectic, complex feelings that are both rewarding and challenging personally and professionally.

Once fulfilment was established as the phenomenon of interest, I looked through the transcripts to find examples of where the nurses had spoken in such a way to demonstrate their fulfilment. For each participant, dasein revealed the phenomenon of fulfilment and I found excerpts from the transcripts to show this. Looking at the excerpts I chose eleven headings that I felt represented an aspect of fulfilment across the twelve interviews. These

were then reduced down further to five headings each of which represented a grouping of the aspects. They are shown in Figure 6. In order to honour the complexity of the stories and represent aspects of experience that were not fulfilment, I also looked at the antonyms for fulfilment which include disillusioned, disappointed, frustrated and dissatisfied. While these did not entirely sum up the mood of the burden and grief shared by the nurses, it was important to analyse these parts of the stories as well.

Figure 7 Identification of descriptors of Fulfilment-as



6.3.2 Unconcealment of the phenomenon

1. 6.3.2.1 Fulfilment as- Passion, privilege and satisfaction

This aspect of fulfilment described the nurse's feeling of reward, purpose and pleasure in their role. Respiratory nursing as a particular speciality was highlighted to contribute to their framing of fulfilment:

I love respiratory medicine, so I am passionate about it.

(Fiona)

I like the mixture that respiratory gives you of the investigations, the education, the support, so you get a mixture of skills.

(Gwen)

I absolutely fell in love with respiratory

(Hilary)

I think it did ignite that love, that little flame for respiratory

(Irene)

I see some of the patients that I actually diagnosed with COPD but 20 years ago, which is amazing

(Linda)

Being a CRNS was acknowledged to be a privilege, recognising it is a position that can offer mutual reward:

The lady I described is one of life's positive people, she is quite inspiring

(Andrea)

looking back, I often think about her, I think about it in a positive way

(Carrie)

Thinking about the role I do is seeing those patients on assessment that are incredibly breathless and seeing them at discharge and they are much improved, and you almost always see an improvement, almost always seeing improvement. Personally, that is great, isn't it? That's a happy place to be.

(Katy)

The rewards of the job highlight the phenomenon of fulfilment:

I find Respiratory patients are generally very grateful for everything we do which is nice and makes me feel valued.

(Andrea)

I think that the more you feel you know, the more you feel you could offer skills and tools to empower people, I think that actually really helps you as well (Esther)

That's one of the joys of working in the Community

(Gwen)

I've had multiple comments: Thank you for coming. Glad to see you, just just a bit of relief that somebody was interested and actually took the time to go and talk to them

(Linda)

Each nurse felt a personal benefit that they are grateful they do a job they enjoy, there is reciprocity in relationships and the people they meet impress and inspire them.

2. 6.3.2.2 Fulfilment-as shared responsibility and professional support

This aspect of fulfilment is focused on teamwork and a supportive workplace. It enabled the nursing work of caring for patients with breathlessness to be shared within the team and to create a supportive team environment:

We are all very close

(Andrea)

we're quite a supportive team actually.

(Belinda)

I'm also lucky because of the team that we are. We look after each other and we're flexible.

(Gwen)

I have a very, very supportive team. We try and make sure that everybody in the team sees them so it's not always the same person sort of carrying that burden

(Hilary)

We're very supportive. my team already knew that me and [my colleague] had had a tough morning because I had to phone them [so] I just talked it through with them after so our support within our team is really good.

(Janet)

This team support was demonstrated through the opportunity to engage in clinical supervision:

Doing a clinical supervision session with somebody that perhaps has similar experiences. All that's needed is quite helpful.

(Katy)

I think everyone would just come in and breathe and just think oh, we can now all share, so I think it is really important to have a safe space for discussions

(Deborah)

A supportive working environment was built from not only within the team but through wider support:

We do have very good team leads and managers

(Hilary)

We had a really good debrief with my line manager and her boss, so that was really helpful to discuss, and I got a huge amount of support going through everything that I had done.

(Deborah)

However, there were also examples where the participant did not feel there was teamwork or support, and this was detrimental to their ability to process their experiences

The support for us just hasn't been there, not once have we had "how you doing", or "you're doing a good job", not that any of us do it for that. But no. Out further afield from our team the supports rubbish.

(Janet)

There was one time when I did mention it to somebody about how awful and how I wish there was more that we could do and how hard I found it. And actually, it wasn't met with any offer of engaging with the conversation and I remember that and you just sort of shrug your shoulders and carry on

(Carrie)

You would probably want to talk it through and, and there's also an element with health care professionals that you want to appear. You don't. You want to be quite, um? stiff upper lip, not perhaps not quite stiff upper lip, but there's always the element that you shouldn't be emotionally involved.

(Carrie)

we haven't got enough staff within the team. If somebody's off sick that means that service has no cover, so somebody else has to cover that service. The care that's given is OK, but it's not proper care.

(Janet)

And the COVID-19 pandemic exacerbated existing issues:

But yeah, but that can be quite hard sometimes. I think not having that time to reflect as clinical supervision at that moment isn't available. So, I think you end up holding a lot of that.

(Fiona)

Well, particularly through COVID as well, but it was very difficult to get clinical support.

(Irene)

Wider support is absolutely rubbish. Covid's made it worse.

(Janet)

The nature of working in the community results in being geographically separate from colleagues and remote working throughout the COVID pandemic resulted in teamwork being more important than ever for many participants. When there were challenges with teamwork, professional support and protected time for clinical supervision, participants found this particularly challenging.

3. 6.3.2.3 Fulfilment-as Accountability and capability

This aspect of fulfilment demonstrated the participants' sense of self: their confidence, experience and the positive affirmation they receive in their role. Their sense of confidence within their clinical role was revealed:

Nurses are the linchpins in the provision of care

(Andrea)

You [know you] can help address some of their symptoms. we make a big difference to those patients

(Belinda)

I do feel more confident that, when he rings me, I know how I can support him and his wife

(Deborah)

I suppose I do have quite a lot of skills with dealing with breathlessness in the moment and people with high levels of anxiety

(Esther)

I think it's important to know that the patients know that you know what you're doing and being in command and that they can trust you.

(Linda)

They shared a deep understanding of what was required to be a CRN, demonstrating their experience:

the essence of being a nurse that a lot of it is being with that patient, almost like, being there with their struggles

(Carrie)

I think as a nurse your whole ethos is about relief of suffering, isn't it? you want to make people feel better

(Hilary)

And I just remember thinking I don't really know what to do, but I know that we need to do something.

(Katy)

So I think I felt hopeful that we could offer him support as well.

(Fiona)

It's knowing not to speak but just be there, just be supportive.

(Katy)

I think it's just being calm really and reassuring.

(Katy)

It was just having that presence there, but I didn't feel panicked by it because I knew that it was a bout of breathlessness for them that we were managing to get on top of.

(Linda)

And from these experiences they recognise the value of what they do:

I visit her monthly. I know she values me because when she was looking for a bungalow, she looked for a property within my area so she could stay in my caseload (tearful). This validates the hard work I put in

(Andrea)

that's what spurs you on to keep going and you know, help you help your patients as much as you can and think you know I am what I am doing is valuable and I want to do the best that I can

(Hilary)

4. 6.3.4.4 Fulfilment-as success and development

This was fulfilment that resulted from a feeling of achievement, new learning and understanding from patient experiences. Aspects of achievement and determination were clearly described and demonstrated as motivating factors within the role:

You can feel achievement [in this role].

(Carrie)

not everybody can do this job

(Esther)

One of the things that I found very satisfying about doing visits for complex [patients] was having the time and the capacity to sit and it was almost like untangling a ball of string because there's quite a lot of things that contribute to it, and it's being able to unravel that.

And I find that quite satisfying.

(Irene)

I think the improvements that he made during that to show him that actually, you know there was there was there was hope.

(Janet)

Framing experiences so there was new learning and understanding to take forward into clinical practice was fulfilling:

He's taught me about oxygen, that it's not the best thing, and if patients don't get on with it it's more trouble than it's worth

(Esther)

It makes me think going forward, how we can do things differently within our team.
every time I see somebody you learn from every experience

(Fiona)

it's all a learning curve, 'cause if that's happening to her and we need to consider that for other people too. Like that Maya Angelou quote 'when we know better, we do better'.

(Irene)

I think [this clinical situation] has influenced how I want to develop the diagnostic hub.

(Irene)

So, I think because I've got all of that knowledge now when I see a breathless patient, I've got an idea of what things might help them and not everything helps everybody.

(Katy)

You can take bits from and learn from a lot of these patients

(Linda)

5. 6.3.2.5 Fulfilment-as emotional understanding

This aspect of fulfilment was revealed through the participants' empathetic connection with their patients:

I can imagine how it feels

(Andrea)

I think it's affected me in that with a lot of input and looking at it through different angles and giving a lot of support and being there regularly right through to the end really helped

(Carrie)

I think well I've not really done anything other than listen to what you've got to say and understood your concerns and acknowledge that what you're going through is difficult and challenging.

(Hilary)

I acknowledge that and I hear you and you know I'm here for you

(Irene)

I felt for her 'cause she just sat and cried in the end and I think she just needed someone to hold her hand and let her cry and just a lot of things came out.

It's nice to have a different relationship with them. I think we probably know more holistically about the patient than the GP does.

(Deborah)

we can get deeper with the conversation and perhaps better understand your patient from an emotional point of view.

(Katy)

It was just a case of, you know, sitting with her, being reassuring.

(Linda)

Attunement revealed fulfilment in the experiences of the participants alongside practical and emotional challenges identified as burden and cost.

6. 6.3.2.6 Burden and Personal cost

There was also a mood of sadness and grief when participants recalled their empathetic connection with breathless patients that left them feeling distressed. This was revealed through burden and cost and accepting compromise. It was demonstrated by how participants adjusted their own expectations of the outcomes of care, challenge and cost to themselves associated with supporting their patients with breathlessness:

You're not going to alleviate it, you know it's part of the breathlessness, it is part of their condition.

(Belinda)

there was almost a feeling that we never actually helped as much as you would have hoped, and I think there was a little bit of a feeling of failure.

(Carrie)

You just get in your car. Sit for a bit. You know, I think that's the thing to do so to try and reflect a bit. And then you've often gotta drive to the next person and then you can. And then, of course, because we're professional, I think once you know you get into that next person's house, then that sets your focus on them.

(Carrie)

But I think there is a lot of frustration with him, and I might have probably wanted to push him a bit more towards that acceptance of the new and he's not ready. So, I've had to step back and go right, this is where we are

(Esther)

Uh, and it's just such an intense. It's an intense symptom, isn't it? And it's often a very sort of stressed, intense environment between the person and carers family, and I think that could be quite emotive

(Fiona)

there's not a lot of room for recovery. Because we're busy this has struck me much more in this role than others. So, I think sometimes there's not that space, you kind of just have to get on to the next thing, really.

(Fiona)

And so you do just sort of feel like gosh, you're racking your brain almost what else can I do there must be something that I can do and I think as a nurse your whole ethos is about relief of suffering isn't it you want to make people feel better and when you're faced with the situation you can't make better that's really difficult and it's not a comfortable feeling to feel helpless and like there isn't anything I can do to make this situation better.

(Hilary)

The expectation for the patient is that she's going to make me not breathless. And well, I'm not. I'm going to help you manage it.

(Irene)

While these aspects of care are explored through the Heideggerian notions in the second stage of analysis, they were present also in the mood and attunement of the interviews, demonstrating the participants held both the burden and challenge alongside the privilege and fulfilment of their work. Recognising that these emotions co-exist highlights the complexity of care delivery that needs further exploration.

6.3.3 The emerging Phenomenon: managing complexity of care through fulfilment

The participants shared themes in the crafted stories around the challenge of caring for patients with breathlessness that describe personal costs, distress and emotional labour. However, beyond this description, revealed through the attunement of the interviews, there is a shared mood with all participants that speaks of a clear sense of positivity, purpose and fulfilment within the role. The research question deliberately asked open questions about the experience of supporting people with breathlessness rather than asking the CRNS participants to particularly focus on a challenging time or a time that was difficult. In this way their accounts, outlined in the crafted stories, reveal the complexity of this care reflecting the challenges, but also the reward and privilege of care provision.

These experiences shaped the participants as nurses and drove them personally, assured in their role. This is complex in that there is not a dichotomous distinction of feeling distressed or feeling positive but there are layers to it (Carrie in Int 3 speaks of layers to respiratory nursing).

'There are lots of layers to it and you can feel all sorts of things with breathlessness.

You can feel guilt. You feel achievement. You can feel sadness. You can feel almost disbelief. Is this really happening and then relief if things do settle. I still feel a relief now if I go to someone's door and they are really breathless but it settles'.

(Carrie)

Many spoke of their recognition of the tenacity and commitment required to be a community respiratory nurse and how, through meaningful engagement with patients they rise to this challenge.

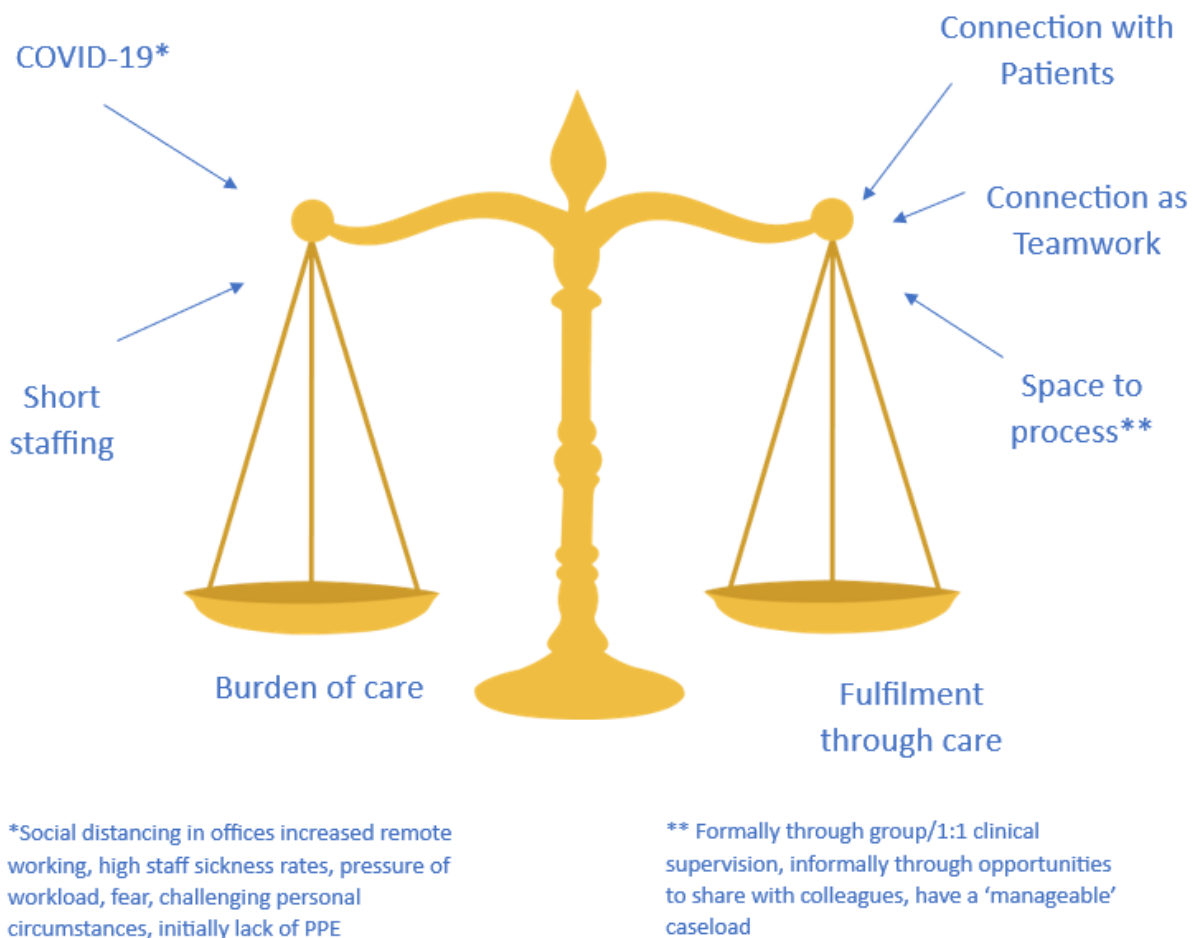
Participants' professional identity as community respiratory nurses is inextricable to them as individuals; "being" a nurse, *their* dasein is shaped by everything in the past, present and future, their thrownness as human beings in their nursing role. This "being" situates them with patients to experience their suffering directly. Being in the patient's home, as a guest, often faced with clinical situations that are challenging (because there are few fixes) throws the nurse into their patients' lives, witnessing helplessness and wanting to do something to help. While this cost is clearly described (often feeling vulnerable and exposed), it is also a privilege that enables connection with patients and families. This connection is fulfilling and drives the participant CRNS. I cannot definitely say what drives them because I did not ask this question, because I was not aware when formulating the questions that fulfilment would be a phenomenon I would be exploring. Gadamer (1975) proposed that new understanding revealed by the to-and-fro of dialog, fusing the horizons of the researcher and participant is central to hermeneutic enquiry and the interpretive paradigm. So, in considering the thrownness of each of the CRNs coming into the job, often with many years of dedication to the profession, their care, empathy and job satisfaction reveals that it is the role itself that offers this motivation.

Connection is important not only with patients and families, but it is also important with their colleagues in their team. Due to visiting patients at home, community teams are geographically dispersed so the opportunity to meet together face to face might just be once a day, or not at all (using online interaction if the team works remotely), differing from other care settings such as a hospital or clinic. While COVID had widespread impact throughout the NHS, the impact for connecting with colleagues was particularly testing for many community teams. They did not have the opportunity to meet together face to face due to social distancing, resorting mostly on online platforms. COVID highlighted the detrimental

effects of this, highlighting the importance of this aspect of the phenomenon. These findings are supported by Mitchell *et al.* (2021) who considered the impact of COVID on community nurses and GPs. They found that COVID was detrimental to the supportive team dynamics that were so important in clinical practice so that community nurses especially felt isolated, compounding their emotional distress at this time.

Having “space to process” patient experiences provides the opportunity to give and receive support informally and through clinical supervision. This space impacts the balance between the distress and rewards of connection. As a result of COVID the balance has tipped so that often distress has predominated over the rewards of connecting with others. This is illustrated in Figure 7 and supports Jagiasi *et al.* 's (2021) findings that an absence of emotional and social support in COVID was detrimental to health care workers wellbeing. Stoke-Parish (2022) found that in addition to this lack of support, the “hero and angel” narrative that was commonly used to describe healthcare workers added to their poor sense of wellbeing because many workers felt a personal sense of responsibility for their wellbeing to live up to this expectation.

Figure 8. The scales of burden and fulfilment: threats and antecedents



The balance of witnessing distress yet connecting with patients resulting in fulfilment has been unbalanced by COVID because the chance to give and receive formal and informal support has been severely compromised. The opportunity for space to process in order to debrief and reflect on situations has been diminished by isolated working. Due to the nature of the work with patients, CRNSs bring themselves to the role so that the emotional costs but also the fulfilment are felt personally. The identification of a connection between workload, patient engagement and 'existential fulfilment' was considered by Tomic and Tomic (2010). They observed that fulfilment for nurses was most likely when their workload was manageable, and the nurse could have meaningful engagement with those in their care and were least likely to feel fulfilled when workload increased.

However, the idea of fulfilment through care being a balance of connection and distress has not been considered and challenges current thinking in emotional labour. Emotional labour is often described in a binary way as a cost to nurses but in considering it as fulfilment balanced by connection with patients, teamwork and “space to process”, a new perspective can be considered.

6.4 Conclusion

The three stages of analysis have demonstrated how crafting stories, using Heideggerian notions and attunement revealed new understandings from participants’ lived experience of supporting people with breathlessness. Analysis suggests that bearing witness to the distress of breathlessness is indeed challenging for CRNSs, presenting discomfort that has been illuminated through the Heideggerian notions. However, attuning to the interviews revealed the phenomenon of fulfilment. When the antecedents of teamwork, connection with patients and space to process are in place, fulfilment can flourish. This nuanced perspective for nurses when bearing witness to distress warrants closer scrutiny and will now be examined in the discussion as new knowledge for clinical practice.

Chapter 7 Discussion: into the clearing

*To say that it is illuminated means that as
Being-in-the-world it is cleared in itself,
not through any other entity, but in such
a way that that it is itself the clearing*

Heidegger: Being and Time 1962 p171

7.1 Introduction

For Heidegger, the phenomena that emerge from the hiddenness of the natural attitude was at the heart of his philosophy. Phenomenology is the means to make that which was invisible, visible by bringing it into the light, stretching thinking beyond the natural attitude and what we already know. For Heidegger a clearing is *Lichtung*, a lighting that can be thought of in terms of emergence from unconcealment. Truth is the unconcealment that 'takes place' in the clearing (Morrison, 2003). However, the light is not an illumination that is switched on out there in the world, rather Dasein switches a light on for herself and in doing so in her interaction with the world (Smith, 2022). The clearing is this ontological space of new understanding that is not a static field but a gateway to understanding.

Therefore, the aim of this chapter is to explore the key outcomes of the analysis, discussing their significance in the context of what is already known about the experience of supporting people with breathlessness. This will be approached by returning to the discussion presented in the background and context for the research (chapter 2) and the literature reviewed (chapter 3) in order to demonstrate how this study advances understanding of the research question.

The key points that have shown themselves through the analysis are the personal and professional challenge of being-with people who are breathless as revealed through Heideggerian notions. These are discussed and considered within the current understanding of emotional labour. I then examine the phenomenon of fulfilment, exploring the findings that, having the opportunity for teamwork, connection with patients and space to process identified by participant CRNSs can be antecedents to fulfilment. This is discussed in relation to emotional intelligence and returning to emotional labour I present new understanding and insights that have emerged as a result of this research and their implications for clinical practice.

7.2 Revisiting the research question

Breathlessness is the biggest symptom burdening people with respiratory disease. The invisibility of breathlessness is well documented (Carel, 2016, McNaughton, 2017, Serresse *et al.*, 2022) insomuch as people who are breathless often stay in their homes, their experience of breathlessness cannot be shared, and it is difficult to measure and quantify. As a result, many health care professionals focus, through the medical model, on respiratory disease rather than the illness experience. This serves to reinforce this notion of invisibility where the multifaceted burden of breathlessness is overlooked (Serresse *et al.*, 2022). Respiratory nurses in all settings support people with breathlessness but for most people with respiratory disease, their needs are best met in their own homes so CRNSs are well placed to provide this care. Supporting people with breathlessness can be very challenging because it is generally a refractory symptom and much of the training for all clinicians is focused on disease management and measurable intervention. Little is known about the experience of nurses supporting people with breathlessness. In order to address this research question, a Hermeneutic Phenomenological study was carried out to reveal the taken for granted understanding of a common experience for CRNSs. By this I refer to the natural attitude adopted in everyday life, where there is a tendency to overlook meaningful

experience by focusing on objects encountered (Crowther and Thomson, 2020). Twelve CRNSs were recruited and invited to an in-depth interview with myself to explore their experiences of caring for people with breathlessness. Through 3 stages, analysis revealed a complexity of findings, some that were expected and others that were unexpected.

The first stage of crafting stories presented the opportunity to be in relation with the data, reading and re-reading the transcripts to crystallise each one into a story that speaks of the participant's experience of supporting people with breathlessness framed by their *dasein* (Crowther and Thompson, 2022). Each story is couched in the nurse's thrownness reflected in the experience they shared.

The second stage considered the experience of caring for people with breathlessness through the lens of Heideggerian notions. These notions revealed that breathlessness presents an existential threat to nurses, speaking to their own mortality, sometimes feeling personal discomfort and professional helplessness. The third stage revealed, through attunement, the phenomenon of fulfilment when bearing witness to breathlessness. In order to describe the different ways fulfilment was seen in the stories, five 'Fulfilment-as' descriptors were identified (figure 6). These descriptors challenge the current understanding that witnessing distress (as breathlessness) for nurses is a wholly negative experience and a form of emotional labour that only leads to burn out and moral injury (Smith, 1992, James, 1992). These descriptors identify a drive and motivation for nurses caring for people with breathlessness through the privilege of care. They also reveal the importance of teamwork, connection with patients and 'space to process' their experiences as antecedents to fulfilment.

In summary, data analysis revealed that the experience of caring for people with breathlessness is indeed practically and emotionally challenging but the CRNSs in the study also experienced a profound sense of fulfilment in their provision of care. In light of literature in this field, fulfilment when witnessing distress was not anticipated but in many ways should be no surprise in a role where nurses form a deep connection with the people they care for.

Parse's (1997) theoretical perspective can be seen within these findings, where human experiences are central to care: both in the giving and receiving. Parse's recognition of the primacy of experience is seen throughout participants accounts and within the ontological approach to analysis.

These findings reveal that supporting people with breathlessness is indeed challenging due to the complexity of the symptom. The notion of breath and breathing, demonstrated through the literature discussed in chapter 3 is fundamental to being alive, "breathing life-giving breath" (Holy Bible, Genesis 2.7) and Prana meaning "breath of life" in the same way that the absence of breath equates with death as depicted in *King Lear* (Shakespeare, 1995) and the Marquesans and new Caledonians rituals at death (Oxley and Russell. 2020). The depiction of breath and breathing across religious texts (the Spirit/Breath of God and its significance to life), in cultural rituals (burying the Dinka chief alive in the hope of permeating his breath to the whole community after death), in literature and arts ("Oh what pleasure to breathe easily in the free air" Beethoven's *Fidelio*), through spirituality and ancient wisdom (Qigong, Tai Chi and Yoga) and seen in the COVID pandemic (people dying gasping for breath due to COVID), reveal it as intrinsic to the human condition. Therefore, in bearing witness to breathlessness CRNSs will be faced with their own ontological questions, framed by their *dasein*, their thrownness and their own reconciliation with being-toward-death as living, breathing human beings. The value of a phenomenological approach to new understanding recognises that in focusing on lived experience, we shed light on this human position and unconceal what has been hidden and taken for granted. Psychologist Alexandra Parvan celebrates the use of literature as a means of illuminating the experience of breathlessness in her poem (Appendix 6) and advocates that through the arts, HCPs might learn more about themselves and the people they care for (McNaughton 2020).

7.3 The challenges of bearing witness to distress as breathlessness

Analysis through the Heideggerian notions revealed that the experience of supporting people with breathlessness, a refractory symptom which cannot be 'fixed', is challenging, can 'sit heavily' and is unsettling for CRNSs despite their knowledge and experience in their field of respiratory nursing. These ideas align closely with those expressed in work previously published during the initial stages of this project (Speakman, Butcher and Schutz, 2021a). However, thinking has progressed as each notion, considered ontically and ontologically, has revealed a different insight into an aspect of care that will be explored.

The participants found leaping-ahead challenging, yet they strove to do this over leaping-in. Leaping-ahead, ontically, is enabling and facilitating as opposed to making an intervention. Examples of facilitating for people with breathlessness might be discussing self-management plans that advise on the use of handheld fans, pacing, pursed lip breathing, inhalers or medications. While these can be helpful, once symptoms become refractory, they will persist despite these interventions. Participants identified it felt easier to 'do' because in not 'doing' they were unable to distract themselves from the presenting situation; exposed to witness the breathless persons' distress and suffering which was a cost to them personally and made them feel professionally impotent. Such was this distress that it made Hilary question their position, examining their place as a nurse if it is not to relieve suffering. This visceral discomfort is described by other participant CRNSs as a significant aspect of leaping-in and leaping-ahead. In not 'doing', they were 'being-with' their patients, alluded to, by Andrea and Hilary, recognising this as an important aspect of care. However, this was overshadowed by the feelings it elicited for them personally. Therefore ontologically, leaping-ahead can be considered personally challenging for participants despite the unanimous recognition of the benefit for patients. Participants' approaches to care differ

from those described by participants in Bailey, Coella and Mossey (2004) study. Here the ward nurses essentially 'leapt in' with their interventions, focusing on physical needs rather than patients distress from breathlessness. This identifies an aspect of care that is not well documented (Speakman, 2018), remains central to therapeutic nursing (Peplau, 1952, Travelbee, 1971, Orem, 1980, Hockey, 1989 and Ersner, 1992) yet has arguably lost its status with the advance of evidence-based practice (Kerr and Rainey, 2021) and the pressures of contemporary care.

This challenge of '*being-with*' is borne out across the study, revealed by each of the Heideggerian notions. When considering the *thrownness* of each participant, their personal beliefs, values and previous clinical experiences shaped their prejudgements and prejudices; to create a unique encounter between each nurse and patient. Each inimitable relationship is fundamental to therapeutic nursing, and in being *thrown*, there are possibilities for both nurse and patient that are future focused. Therefore, recognising the individuality each nurse brings to the CRNS role is important when acknowledging both strengths and challenges of the individual. The research interview enabled all the participants to explore elements of the role from their own thrown perspective, attuning to how each participant makes sense of the world and focusing on what matters to them. Esther identified her frustrations with the gentleman she described, making the link to her previous experience in clinical practice and consequent prejudices. My own identification with Andrea's position (reflexive diary entry following Int 1 5.2.3.3) highlights how personal beliefs can negatively influence the ability to reconcile the challenge of witnessing distress. And Fiona's acknowledgement that, in bringing herself personally to her role as CRNS costs her emotional energy, so she often has nothing left for family and friends. The study reveals that recognising the thrownness of each nurse can be a gateway to supporting CRNSs in this demanding role to feel supported, heard and remain in practice. Gullick and West, (2020) identify the challenge of being-with as "nursing in the self-mode" (p654), and suggest nurses that seek connection, openness and allow themselves to be vulnerable and demonstrate authenticity. Rouf's (2020) poem

(appendix 7) captures the deep connection between the doctor and patient and resonates with participants' experiences echoed here.

"A bouquet of tear-stained tissues

Tumbled

From her hands

Into the clinic room bin.

They felt like crushed white roses.

She left fingerprints everywhere..."

Rouf (2020)

The qualitative aspects of the encounter for the doctor illustrates their subjective experience of being-with and bearing witness to distress in caring for another person. p168

These experiences for participants are echoed in Jellington *et al.* 's (2016) findings, that worsening refractory breathlessness is uncomfortable to watch for nurses, unable to affect the patient's experience with any meaningful intervention.

The notion of *being-toward-death* was revealed through the participant CRNSs experiences of supporting people with breathlessness. Severe breathlessness is synonymous with grave illness and imminent death so in witnessing this, participants were faced with their own existential threat of being-toward-death which influenced the care they could give patients.

This was seen throughout the crafted stories as challenging for the participants, and for Esther "*..the thing I hate most.*" Esther's position, preferring to be busy and 'doing'; caught up in the mundaneness of the 'they,' mirrors the majority of nurses in the studies that contributed to Gullick and Wests' (2020) meta-synthesis of phenomenological studies. This study modelled analysis using the Heideggerian structures of 'being-with' in the nurse patient relationship. Described as 'existential abandonment', the nurses in Gullick and West's study were mostly uncomfortable being alongside death and talking about dying which often left "vulnerable patients adrift" (p653), yet this is not seen here. Most of the participant CRNSs came alongside their patients (the exception was Esther, discussed in more detail in due

course) despite their personal discomfort. 'Coming alongside' refers to their readiness to engage with individuals and bear witness to their illness and imminent death. They talked about discussing the persons' preferred place of death (Belinda), "*we planned it and worked together*" (Carrie), "*I think planning for a good death is a big part of our job.*" (Janet) and Linda had to speak directly when she was called and found her patient was dying: "*I was trying to explain to the relatives that actually I think your mum, your wife is dying*". Other participant CRNSs alluded to bearing witness to death and dying in their role as something they actively did and although it was challenging, was felt to be an important aspect of care. Facing the authenticity of being-toward-death, temporality and meaningful existence could be a factor contributing to the phenomenon of fulfilment revealed in the CRNS role. Yet their discomfort was also evident: Andrea said, "it really hurts me, Carrie talked of " *a sense of unease*", "*it can sit quite heavily with you*" (Fiona), "*[it's] a very uncomfortable feeling*" (Gwen) and for Hilary it "*lays heavy on you*". This suggests that like the notion of leaping-ahead, while being-toward-death might be personally challenging, participant CRNS overcome this, endeavouring to support patients toward death knowing this is an integral part of their role. This finding is consistent with other research that nurses find 'being-with-dying' challenging (Hylton Rushton *et al.* 2009, Haraldsdottir 2011, Speakman 2018) and as a consequence, nurses in Hylton Rushton *et al.*'s. (2009) and Haraldsdottir's (2011) studies avoided engaging in conversations about death and dying. This study reveals that participant CRNSs demonstrated authenticity in being-toward-death that left them feeling vulnerable, yet they did not shy away from these challenging conversations.

The experience of witnessing breathlessness was identified by Carrie:

"[We] are very involved so when they are struggling with symptoms it can be like watching a loved one."

(Carrie)

This comment demonstrates Carries' care for her patients and personal distress as a result, but the wider data collected does not suggest that participants experienced vicarious

breathlessness in the same way as Johnson and Gozal (2018) described it as experienced by caregivers who regularly witnessed breathlessness. This 'vicarious breathlessness' referred to by Johnson and Gozal is linked to carers' own distress, contributing to their loved ones' increased chance of presentation to Accident and Emergency (Hutchinson, Galvin and Johnson, 2020). Although CRNSs identify with the people they care for there is no doubt they are more removed from the situation as visitors in the home, perhaps with access to escalation of help if required and with a specific role to fulfil unlike family carers who are often inextricably linked with their loved one. This does not diminish Carrie's position, in fact the repeated exposure to distress through her role in supporting people with breathlessness left her vulnerable and unsettled.

Recognition of this '*state-of-the-uncanny*' notion particularly highlights the aspects of the role for CRNSs that leaves them unsettled. Interviews were conducted within the COVID pandemic, and its impact was reflected emotionally and practically within the crafted stories of all the participant CRNSs. For Janet her frustration was explicit at her organisation:

Wider support is absolutely rubbish. Covid's made it worse. I think the NHS support like senior senior managers haven't got a clue what we do.

(Janet)

whereas Carrie reflected personally on the implicit limitations the pandemic brought for her:

I feel like perhaps I could have done better by visiting more and being there, but it was in March [2020] when Covid started, and we couldn't do that

(Carrie)

The nature of caring for people with breathlessness, knowing there are no tangible fixes was challenging for the participants, for whom their dasein was being in the world of their

patients. Irene felt somewhat inadequate that, as a specialist, there was not “*some kind of miraculous new concept*” she could share with the nurses who looked to her for guidance when advising about supporting people with breathlessness. Gwen, Carrie and Hilary also felt inadequate and ‘*a sense of unease*’ that when visiting their patients, they knew that there was nothing really they could do to make a difference to their symptoms. This position could be understood in the way that Heidegger saw *dasein* as structurally inauthentic and invariably conforming and ‘falling’ into the world of ‘the they’. Walsh (1999) identifies that for nurses this translates to the taken-for-granted inauthentic ‘they mode’, caught up with work pressures, prioritising a very functional approach and caught up with everyday concerns rather than providing authentic, engaged, connected care. For Esther, her angst was more to do with adjusting to the role of CRNS, but like Carrie and Hilary she could reflect on this discomfort as Heidegger described, as an opportunity for transformation; endeavouring to look beyond her mantra of “do, treat, do” to facilitate self-management and work with the breathless gentleman in the scenario she described.

The notion of *machination*, described by Heidegger (1962), refers to our relationship with technology rather than the technology itself, revealing that for some participants this was a practical way to distract from being-with and being-toward-death. While installing oxygen machines, hospital beds and other equipment is important in care, for Belinda, this was the focus of her story despite my prompts for her to describe her feelings. According to Heidegger, if machination is the exclusive view over other modes of being, we risk the abandonment of being where the nurse is concerned only with the bare facts and concepts that are presented with no concern for the patient ‘being’. This can lead to prioritising calculable, objective measurements removing one from being-with and the stillness of hidden growth (Thomson, 2011). For people with breathlessness there are few objective measurements that can quantify the experience, so machination is a distraction from meaningful engagement. Bailey, Coella and Mossey (2004) found nurses in their study

prioritised technical interventions for people with COPD over provision of emotional care, highlighting a recommendation by the authors for the importance of individualised care. Participant CRNSs generally seemed more comfortable sharing what they had done practically for their patient, rather than how they felt. This was seen in the interview transcripts in the 'to-and-fro' of questions, asking participants to share how they felt rather than what they did. The following example is from the transcript of Interview 2 with Belinda, I asked her to describe how she felt caring for a patient who was breathless, her answer focused on what happened, what she did and how they felt despite trying to get her to describe how the experience was for her:

Me: So, you said that you witnessed an episode when you were there and he was really breathless. What was that like for you?

I'm interested in what you felt, you said it was frightening for him and his wife, but what were your thoughts and feelings around that episode?

Belinda: I think it was just making sure that. I was doing everything that I could. I knew that, you know, he was on his oxygen, and he had some lorazepam whilst I was there, and his wife was lovely with him.

The desire to quantify what we do is prevalent across nursing (Ebright *et al.*, 2003, Potter *et al.*, 2004, Wolf *et al.*, 2006) seemingly prioritising functional 'doing' activities over the more complex qualitative aspects of care. Tasks are easily quantifiable as Wolf *et al.* (2006) demonstrate when describing nursing work. These research studies, conducted in hospital settings are not entirely applicable to community nursing due to the uniqueness of inpatient care facilities. However, the focus of research describing what we 'do' is pervasive in a health care culture that prioritises 'doing' over 'being' so it is unsurprising the CRNSs in the present study were initially focused in the interviews on what they did for their patients. In respiratory nursing, focus on the specialty can often overshadow the importance of holistic patient care. Training in enhanced communication skills and the complexities of recognising dying are important skills to equip CRNSs for their role. This recurrent theme of the challenge for participant CRNSs of '*being-with*' their patients who were breathless (despite

recognising it is an important aspect of care) as opposed to 'doing' emerges throughout the study, explored through the Heideggerian notions. It left them feeling vulnerable, exposed and somewhat compromised because patients' care was already medically optimised so all they could give their patients was themselves. This giving of self had a cost to each nurse and the findings of this study are consistent with extant literature regarding nurses bearing witness to distress (Sawbridge 2016, Salyers *et al.*, 2017, Speakman 2018, Speakman, Butcher and Schutz, 2021a). This is a challenging component of care that can be described as an aspect of emotional labour that will now be discussed.

The second part of the analysis using Heideggerian notions gives primacy to the data but the philosophy illuminates meaning in the data. In moving on to explore understanding of emotional labour historically to the present day, I put current findings in a context which, following discussion on the phenomenon of fulfilment and emotional intelligence, a new understanding of emotional labour is presented.

7.4 What is emotional labour?

The term emotional labour was selected for this study over moral distress because it was felt to be more relevant to the field of community respiratory nursing. The reasons for this are illustrated in the following discussion of the 2 terms.

Emotional labour was defined by Hochschild (1983) as

“the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial safe place”.

Hochschild, 1983 p29

It was further described by James (1989) in nursing as

“The labour involved in dealing with other people's feelings, a core component of which is regulation of emotions”

James, 1989 p15

Emotional labour therefore relates to the unseen component of nursing work where nurses suppress their own emotions such as grief, anger, loss and despair to prioritise that of the person they are caring for and supporting.

Moral distress was a term first coined by Jameton in 1984. It relates to the psychophysical strain experienced by nurses as a consequence of moral challenges in clinical practice (Giannetta *et al.* 2020). These can be considered as moral uncertainty, moral dilemmas and moral distress. Moral uncertainty is doubt about what is morally right in certain situations, moral dilemmas occur when two or more principles or values conflict requiring opposite or incompatible courses of action and moral distress arises when

“One knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action”

Jameton, 1984 p6

Moral distress has been widely discussed and highlighted as a cause of burnout and loss of job satisfaction (Austin *et al.*, 2017), poor patient care (Oh and Gastmans, 2015) and resulting in poor psychological health and wellbeing for staff (De Veer *et al.*, 2013).

Examples of moral distress in the literature in clinical practice describe situations where there are clear choices for intervention and treatment and the nurse feels compromised by the decisions made (Ferrell, 2006, Lachman, 2016), often originating from surgical and oncology wards where treatment options exist. Other examples come where there are emotional dilemmas as a consequence of illness (Manara, Villa and Moranda, 2014), originating from Intensive Care around information sharing with wider family.

In community respiratory nursing, due to the refractory nature of symptoms, there are few decisions to be made around treatment options. Medical ceilings of care are reached as disease progresses and nursing challenges are around helping individuals to live well with a high symptom burden that will inevitably progress. Decisions around advanced care planning and resuscitation are important components of care but these are not moral dilemmas, they

involve professional confidence and competence and are indeed fulfilling aspects of provision of care.

Emotional labour will however be a component of care, as demonstrated in the present study, as nurses inevitably mask their own feelings to prioritise the care of others. It is for this reason that the term emotional labour is used, explored and its implications challenged in this study.

Emotional labour as described by James (1989) is “the labour involved in dealing with other people’s feelings, a core component of which is regulation of emotions.” (p15). Nicky James, a nurse sociologist, conducted her research as a participant observer in a hospice in 1986. She extrapolated Hochschild’s (1979) research on the experience of air stewardesses⁴ to nurses, identifying that emotion work is regulated by social exchange. This differs from the emotive experience of normal adults in everyday life which Hochschild describes as ‘orderly’, where individuals manage their emotions situationally. Air stewardesses were described as surface acting (consciously changing outer expression to make inner feelings correspond with appearance) or deep acting (changing their feelings from inside using a variety of methods such as imaging, verbal and physical prompting so that only desired feelings are shown) and both can be unconscious or partly conscious (Smith 1992). James (1986) described how emotions such as grief, anger, loss and despair were difficult to witness and challenging to respond to for nurses because they did not fit in with the standard idea of workplace skills. She identified that the nurses’ management of their emotions in the workplace as Hochschild described and it shared many of the connotations associated with labour (hard work, productive work, labour as pain, sorrowful and difficult) but due to interfacing with women’s work were difficult to quantify. The term ‘labour’ differentiated ‘feeling work’ undertaken as part of a paid role compared with that

⁴ Air stewardesses would be called cabin crew nowadays, however as Hoschschild referred to this role intersected with being female, the original term has been kept

undertaken in everyday life. James concluded that in both the public and private domain emotional labour is unrecognised, unrecorded and unrewarded. This notion of emotional labour as care, presented by James in relation to Hochschild's work, was developed by Smith (1992). Smith continued with the focus on emotion work as a burden and cost to nurses but identified its importance for patient care.

The understanding of the need for nurses to engage with patients in a meaningful way paved the way for primary nursing (Salvage 1990), The Nursing Process (McKee, 1992) and 'therapeutic nursing' (Ersner 1992, McMahon 1992), identifying the importance of person-centred care (McCormack 2016). However, the focus of emotional labour as care that is a burden and cost within nursing remained predominant, partly because it is difficult to define. Anne-Marie Rafferty admitted her frustration with 'care' in a discussion with Madeleine Bunting in 2020:

"Eighty percent of the universe is dark matter, but scientists can't find it- it's the same with that ineffable part of care. It's just as big and hard to pin down."

(Bunting, 2020 p104)

The premise of emotional labour as a burden and its link with burnout has been well researched (Dall'Ora *et al.*, 2020) and still endures. According to Bunting (2020), this is due to the complexity of care. Care is often hidden, women's work: tacit and taken for granted. Bunting explores the origins of the invisibility of care to post second world war Britain when middle class women, no longer supported by domestic servants to assist with running the home and raising children, began to go out to work. Previously the complexities of running a home: the washing, cleaning, shopping, cooking; caring had been delegated and seamlessly taken care of with little acknowledgement. Technological breakthroughs with washing machines and dishwashers transformed some of the practicalities of managing the home and fuelled the illusion that these jobs could be squeezed into weekends and evenings. Care responsibilities in the family have also changed over the last sixty years when children commonly left home at 15 to take apprenticeships. The high expectations that now fall to

parents (especially mothers) to support children emotionally and practically, can be a 25-year project as young people's independence is more uncertain and provisional due to spiralling house prices and the cost of living. The care needs of elderly parents often add to these demands. All these roles can be deeply rewarding but the intensification of demands can be lost in the gendered definition of what it means to be a woman, a wife, a mother, sister and daughter. These taken for granted assumptions and ignorance about what women had been doing with their time and their invisibility, according to Bunting, is what lies at the heart of the current crisis in care in the UK. This is supported by Theodosius (2008) who, in summarising Hochschild's position, argued that women undertake more emotion work in the home because they offer it to men like a gift to offset their dependence on them for financial and material support. However, as more women are now financially independent (72% of women work in 2023 compared to 56% in 1980: Statista 2023) this transcends Hochschild's earlier assumptions, yet the predominance of care remains in the domain of women today. As long as caring remains culturally defined as 'natural for women' and the state promotes policies that idealise family life where women nurture and care for others (Finch and Groves, 2022), caring will remain invisible and underappreciated.

The crisis of care is framed within chronic underinvestment in both health and social care in the UK, exacerbated by challenges to recruit and retain nurses and care staff. The COVID pandemic has shone a light on this crisis, highlighting the value of care as people died separated from their loved ones, initially with little medical intervention that could save them, with only nurses present to ensure they had dignity and comfort at the end of life. In these situations, the value of care was recognised; of being-with individuals bearing witness to distress and death. In acknowledging this important gift of care to patients, not merely a taken for granted aspect of the role assumed to be done because they are nurses, the true value of care has been realised revealing the altruism expected of nurses and the importance of care to all, as Slettmyr *et al.* (2023) recognised.

This discussion outlines emotional labour framed within a gendered perspective that care is invisible yet central to the needs of many, undervalued yet precious and tacit yet an presumed aspect of nursing. Its complexity can distract from the experience of giving care, which, as the present study reveals can be both challenging and fulfilling.

7.5 The experience of fulfilment

The phenomenon unconcealed was fulfilment, rather than resilience or 'anti-burnout'. This use of positive rather than neutral language in itself reveals much about the experience of supporting people with breathlessness. Fulfilment manifests in a variety of ways in each of the crafted stories, it was reduced to five descriptors that illuminate something different about each area of fulfilment embedded within participants' experiences (figure 6). The descriptors show fulfilment revealed in encounters when participants spoke positively about their role:

I find respiratory patients are generally very grateful for everything we do which is nice and makes me feel valued.

(Andrea)

but is also revealed when nurses faced challenging experiences as Linda supported a lady who sometimes got angry with those present when she was breathless:

It was just having that presence there, but I didn't feel panicked by it because I knew that it was a bout of breathlessness for them that we were managing to get on top of.

(Linda)

The word *fulfilment* originates from the mid thirteenth century term *fullfyllan* to 'fill up' or 'make full', referring to a sense of completion. It was used in reference to Biblical prophecy as to 'do, perform; carry out, consummate, complete, satiate, satisfy or gratify' (Online Etymology Dictionary, 2023). It is future focused, resonating with Husserl's use of the term *intentionality*. Although Husserl's focus for intentionality was on experiential subjectivity and worldly objects (Zahavi, 2019), Heidegger progressed this thinking, identifying this as a

significant dimension for dasein of being-in-the-world (Heidegger, 1967). Fulfilment is defined by the Oxford English Dictionary as “the achievement of something desired, promised or predicted.” Fulfilment in the context of nursing can therefore be considered as an expectation, shaped by dasein that is realised, something that has been promised and is predictable. This leads us to ask ‘what is desired, promised or predicted being a nurse?’ There is little research focused on this specific question, but Bjerregaard *et al.* (2017) considered the question of what motivates nurses. They asked care-workers (a combination of qualified and unqualified staff) about their motivations for work and identified fulfilment, belonging, and valuing as three core themes with an overarching theme of shared experience. Fulfilment was described as helping clients (for which they received appreciation and satisfaction) having realistic expectations, feeling needed and being indispensable to others. Bjerregaard *et al.* (2017) identified fulfilment as motivated by intrinsic or extrinsic factors, or a combination. Where intrinsic factors were the primary motivators there was a better, more sustainable motivation than when extrinsic factors such as money and prestige were motivators. The present studies' data suggests that intrinsic factors were the primary motivators for the participants with connection, empathy, feeling valued, privilege and job satisfaction cited along with others as bringing fulfilment.

Perry (2002, 2007, 2008) has written extensively about achieving fulfilment in nursing. Her research has sought to identify what leads nurses to fulfilment concluding that core values, mission and altruism for each nurse shape their approach to care and strive for fulfilment. Perry identified that moments of connection with patients were particularly important for ‘exemplary’ oncology nurses (identified by their colleagues and seniors) to feel fulfilled and avoid compassion fatigue (Perry 2008). The ‘exemplary’ oncology nurses that contributed to Perry’s findings (2008) shared similar attributes to the present study’s participants. Exemplary nurses never gave up, they knew that there was always something more they could do. Sometimes all they could do is be present and witness and never abandon the suffering person. This has echoes of several participants of this study (for example Hilary

and Gwen). My recruitment criteria were to speak to CRNSs with an interest in supporting people with breathlessness. It appears that CRNSs with an interest in this field are nurses who are motivated and proactive to take part in research. This is an important consideration in discussing the strengths and limitations of my research findings.

Perry (2002) suggested that being fulfilled can protect nurses from harm:

“Nurses who are living their missions do not burn out. Instead, they burn, they glow, fulfilled by knowing that each small gesture of caring makes a major difference to another human being”

(p4, 2002)

This idea that meaningful engagement with patients is fulfilling is supported by Gray (2009), who, in challenging the idea that emotional labour results in burnout and distress, found that it enables meaningful relationships to be forged between nurse and patient that foster intimacy and disclosure and are sustaining for patient and nurse. This concept of *meaningful work* was developed by Lee (2015), as an antecedent to fulfilment. Yet given the complexity of nursing work, while the present study’s data resonates with Perry (2008) in that participants often felt a sense of satisfaction despite bearing witness to distress, the context and timing of this study is very important to acknowledge, particularly shining a light on the challenges the nursing profession is currently facing. As I collected data during COVID I cannot avoid the reality that the experience of delivering nursing care has taken its toll on many nurses and is now framed within a political climate of staff shortages, increasing need associated with an ageing population, high inflation, static wages and staff exhaustion as a fallout from a global pandemic. Although the participants demonstrated fulfilment throughout the crafted stories, these accounts must now be considered within an increasingly challenging climate. At the time of writing nurses in the UK are on strike due to low pay, staff shortages and patient safety. Following the COVID pandemic, nurses are emotionally exhausted (Petersen, Wendsche and Melzer, 2022) yet keen to maintain expectations of themselves and others to remain altruistic in their care provision (Slettmyr *et al.*, 2023). For

anyone who desires to help others, nursing provides the perfect avenue. Yet the promise of fulfilment and reliance and the need for altruism as a vital component of the role in order to recruit and retain nurses in this current climate feels like an untruth and an injustice because, while opportunities to care still do exist, these factors offer a particular challenge in the present climate to be a nurse. It therefore feels important to present the experience of fulfilment with the antecedents revealed through analysis that enabled the participants to feel fulfilled.

7.5.1 The importance of 'space to process' and teamwork

Analysis revealed that the phenomenon of fulfilment for participants is framed by the antecedents of seeking connection with colleagues (as teamwork) and with patients and having space to process clinical encounters. The data suggest that when these are in place and there is opportunity for a deep connection between nurse and patient that fulfilment can be achieved. This will now be discussed. Following on from this I also explore the notion of emotional intelligence in relation to fulfilment. I then suggest reframing the term emotional labour taking into account the feminist, historical and professional perspective to pull together these new understandings, taking a different perspective to progress thinking and achieving fulfilment in practice.

7.5.1.1 Teamwork and connection with patients

The value CRNSs in the study placed on teamwork was consistent across all twelve interviews and is redolent of other research focused on emotion work where the importance of teamwork was recognised (McQueen, 1997, Tutton and Langstaff, 2015, Blomberg and Sahlberg-Blom 2007, Petersen, Wendsche and Melzer, 2022). Acknowledging nursing as a shared endeavour amongst peers meant that teamwork was central to feeling supported in practice; recognised by Maslach and Leiter (1997) as one of six work areas that are particularly important when preventing burnout in nursing staff. Teamwork enabled participants to be aware of their colleagues' workloads in order to be equitable:

We try and make sure that everybody in the team sees them so it's not always the same person sort of carrying that burden

(Hilary)

Or if they are they are having a difficult time:

my team already knew that me and [my colleague] had had a tough morning because I had to phone them [so] I just talked it through with them after

(Janet)

Some teams did clinical supervision together which gave them the opportunity to connect through clinical practice. This enabled them to gain shared understanding of the clinical problem as well as sharing knowledge and expertise, suggested by Tutton, Seers and Langstaff (2008) as ensuring nurses are able to deliver the best possible care. Deborah's choice of words regarding team clinical supervision particularly resonates for this study:

I think everyone would just come in and breathe and just think oh, we can now all share

(Deborah)

COVID was particularly challenging for teamwork in community nursing teams who, in an attempt to maintain social distancing and adhere to guidelines, were encouraged to work remotely or from home, avoiding attending the office where possible. Carrie was advised to shield for personal health reasons and identified this as a very isolating time both personally and professionally. This experience resonates with data collected by Mitchell *et al.*, (2021) who identified in their web-based UK wide survey conducted after the first COVID-19 wave, that community nurses felt particularly isolated and had more emotional distress at this time due to their workload and their perception that their contributions were less visible than hospital care in the pandemic response. Their data showed that some teams pulled together and became stronger and more bonded, and support from colleagues was highly valued although formal psychological support was lacking. They identified the need to build trust and supportive team dynamics following this period. These research findings are echoed in the present study and highlight the importance of building effective teams. Maben *et al.* (2023) equated teamwork with psychological safety and '*speaking up*' as prerequisites for

improvement and priorities for enhancing quality and safety in healthcare. The positive outcomes when these are in place include better communication, knowledge sharing, learning behaviour, creativity, innovation, engagement and performance in the delivery of clinical care (Maben *et al.* 2023). From this it is clear that there is good evidence that acknowledges the importance of fostering teamwork for both clinician and patient outcomes.

The fulfilment of connection between patient and nurse is also well documented in the literature (Bevis and Watson 1989, Ersser 1992, Perry 2008, Tornoe *et al.*, 2015) and speaks of the reciprocity of the therapeutic relationship. This reciprocity, enables a connection that:

“allows the one who is cared for to be the one who cares, through the reflection of the human condition that in turn nourishes the humanness of the care provider”

(Bevis and Watson, 1989, p132).

This is borne out by the data in the present study which revealed the opportunity to connect with patients as an antecedent to fulfilment. Participant CRNSs recognised the reciprocity of relationships with their patients which helped them personally:

I know she values me because when she was looking for a bungalow, she looked for a property within my area so she could stay in my caseload, (tearful) I feel this validates the hard work I put in and i recognise that if I am getting it right with this lady I can model those behaviours with other patients.

(Andrea)

It meant so much to Andrea that the lady she cared for would demonstrate her appreciation, desire for familiarity, continuity and reassurance by buying a new home within the geographical area of Andrea's caseload. Andrea sought authenticity in practice, bringing meaning to her personal and professional lives. This sense of meaningful engagement is supported by both Morse *et al.* (1991) and Perry (2008) who suggested that reciprocity reduces the risk of burnout (referred to by Perry as compassion fatigue) for nurses when they engage in meaningful relationships with patients. Gullick and West (2020) identify that

when nurses seek connection with their patients this is a pathway to *being-with*, sharing their dasein and achieving authentic care. They recognised that several authors link the importance of connection and knowing the patient to job satisfaction (McIlfatrick *et al.*, 2006, Pieranunzi, 1997 and Sabo, 2011). Yet while these reciprocal relationships were celebrated amongst participants, there were views held that suggested somehow getting close to patients was unprofessional:

Some of our teams have the same patients [that they] see. I think that's not healthy for them or the patient, I think it can be really lovely in terms of the relationship that you have, but then you can move away from the professional role and what you're trying to achieve sometimes, and you don't always know everything about what you're trying to do for that patient.

(Esther)

Esther voiced her concern that to engage personally would diminish her professional relationship with her patients. This is reminiscent of Morse *et al.* (1992) who suggested that four types of mutual relationship will emerge dependent on the engagement between patient and nurse: a clinical relationship, a therapeutic relationship, a connected relationship or an over-involved relationship. Esther seemed content with a clinical relationship and does not wish to move beyond this which, from the data, appears to be unusual. The other participants demonstrated they enjoy therapeutic, connected and even over-involved relationships with their patients. Perhaps Esthers' struggle with community nursing, contrasting especially the nurse patient relationship in the the acute sector where she had spent the majority of her career, was her reluctance to challenge the dichotomy she perceived between herself personally and professionally as a nurse. This challenge for Esther demonstrates the significance of dasein, being her authentic self shaped by her thrownness that informs her lived experience of being a CRNS. Esthers' struggles are reflected in Alasad's (2002) discussion of the challenge for acute care nurses to balance the

art and science of nursing, reflected in their technical competence versus their therapeutic relationships.

Esthers' view is not uncommon as Carrie suggested:

There's always the element that you shouldn't be emotionally involved. Still, maybe your depth of feeling shouldn't have gone that far, but actually if you have a relationship, a long-term relationship with that person. And even if you don't actually, I think you are bound to feel; it leaves you with a bit of a sad feeling. And the opposite really, if something happens it can leave you with a sense of achievement for yourself and relief for the patient as well.

(Carrie)

Carrie shared her experience of investment in patient care despite awareness that some colleagues might disapprove. This is consistent with Gray's (2009) findings where several nurses recognised that emotions were seen as "weakness" (p171) by other staff, senior nurses and doctors. Yet Carrie suggested that 'having feelings' is part of any relationship, highlighting the difference between community and acute inpatient nursing where care is more short term. This is a consideration that can limit the generalisability of nursing research that is focused on acute care and returns again to the dearth of research focused on emotion work and community nursing.

The term 'Nursing as Therapy' was coined in the 1990s by McMahon and Pearson (1992) and Ersser (1992) and celebrates the benefits of meaningful engagement for therapeutic care, for both nurse and patient. Ersser's ethnographic study of the nurse-patient interaction demonstrated its importance as a component of therapeutic care which endures today. Erssers' study findings resonate with aspects of the present study such as the importance of "presentation of self" (of the nurse- as dasein) (Ersser, 1992 p64), "support and caring" (as leaping in and leaping ahead) (p70) and the value of "being with" (p78). While these aspects of care are framed as essential, central components of care (McQueen, 1997, Smith, 1991, Gray, 2009), they remain invisible 'emotion work' by nurses, suggesting why this remains challenging to define but integral to the CRNS role.

7.5.2.2 Space to process

“... sometimes there's not that space, you kind of just have to get on to the next thing, really.”
(Fiona)

“you have to kind of park it for the rest of the day, while you do your other work”
(Hilary)

Recognition that bearing witness to breathlessness is emotional work was acknowledged by all of the participants. The challenge of this was seen by there not being time and space between visits to process the emotional experiences they faced. It was recognised by the participant CRNSs that this was particularly evident during COVID where the opportunities for formal clinical supervision (either in groups or as one to ones) was not protected time, there were fewer opportunities to informally meet with colleagues due to remote working and caseloads that increased due to more staff sickness and a larger volume of work. This experience of the participants is supported by Mitchell *et al.* (2021), Beebe, McKague and Wallington (2022) and Glast *et al.* (2022) in their studies examining the nurses' experiences of working through a global pandemic which mostly speak of a lack of emotional support from organisations that led to fractured teams and isolation for community nurses. Jagiasi *et al.* (2021) identified that lack of emotional support, being female and working on the frontline increased prevalence for health care workers of anxiety, depression and insomnia during and following the pandemic. While the pandemic was an exceptional period of time, it highlighted the need to have robust systems in place that ensure community nurses are in touch with their teams and not isolated. It is clear that the consequence of not having space to process when bearing witness to distress will have both a personal and professional impact on the nurse in their delivery of patient care, stepping back from meaningful engagement with their patients (McIlfatrick, Sullivan and McKenna. 2006).

There is little research focusing directly on this idea of 'space to process'. Gray (2009) examined how emotions are managed in nursing work and concluded by saying that it is through engaging in emotional labour that nurses have space to engage with, reflect upon and manage their own and others' emotions, thus improving practice and the standard of patient care. Gray's conclusion appears somewhat superficial in regard to my own findings which reveal it was due to engaging in 'emotion work' that the CRNSs needed the space to process. However, in light of Menzies work (1960s) when nurses, struggling with many of the challenges similar to today of recruitment and retention coped with this by deliberately disengaging from emotional work in favour of task-oriented work. I think Gray implies being authentic is beneficial to both nurse and patient, which is supported by Morse *et al.* (1991) as discussed earlier. Blomberg and Sahlberg-Blom (2007) support the need for nurses to have space to process and recognise the way in which 'difficult [clinical] situations' are handled is pivotal to the outcome for staff and patient care. Their participants recognised clinical supervision as a positive way to achieve this with their team.

The benefits of Clinical Supervision (CS) were demonstrated by Cutcliffe and McFeely (2001) as first and foremost providing support for clinical nurses that gave them 'time and space'. The process of CS, self-reported by nurses enabled them to engage in

"intellectually challenging and demanding work, enhanced and enrich their practice and safety, they felt nurtured and grew and were open to a fresh encounter"

(Cutcliffe and McFeely 2001, p317)

by participating in the formal sessions. This is supported by Jones' (2001) study, also self-reported, of Macmillan nurses involved in CS where their encounters enabled opportunities for personal and professional growth, giving nurses

"protected space to make sense of their internal worlds"

(Jones 2001, p27)

In both these studies the nurses were in group supervision and the perceived benefits appear to be as much from their interactions with their peers as from having protected time for CS. Further research is needed to compare the benefits of group and one-to-one CS.

Despite CS being introduced nearly 30 years ago as a means of clinical governance (UKCC 1994), the present study indicates that its provision is patchy. Of twelve participants, nine currently receiving CS but only three of these felt it was useful (Belinda, Deborah and Hilary). Several of the CRNSs did not have any CS at all (Fiona, Irene and Janet) and as a result arranged their own (Gwen and Linda) and one did not feel the group supervision she engaged met her needs (Carrie). For some CS was not protected time being cancelled at short notice (Andrea and Esther) and others felt their organisation offered little formal support that was noticeably worse due to lockdowns (Irene and Janet). The COVID pandemic saw face-to-face meetings cancelled, for which the participant CRNS felt that they had suffered:

I think not having that time to reflect as clinical supervision at that moment isn't available. So, I think you end up holding a lot of that.

(Fiona)

The present study identified that the work of a CRNS can be isolated especially in rural settings covering large geographical areas. The autonomy of the role, visiting patients in their own homes often with complex clinical and emotional needs requires nurses to seek out support unlike a hospital setting where nursing colleagues are least physically present and may benefit from fortuitous encounters.

These antecedents of fulfilment as teamwork, nurse-patient connection and space to process together highlight the importance of developing cultures within organisations that value the experience of staff which will in turn enhance patient experience. This is supported by Tutton, Seers and Langstaff (2008) who suggested a positive culture not only enables these antecedents to fulfilment but help to retain the existing staff and ease recruitment. The

antecedents also suggest a requirement of emotional intelligence on behalf of the nurse which will now be explored.

7.6 Emotional Intelligence and its link to emotional labour

In their study of nurses caring for people at the end of life, Blomberg and Sahlberg-Blom (2007) concluded that therapeutic use of self was determined not only by the experience and education of the nurse, but also aspects of self-identity such as self-knowledge, maturity and security suggesting the importance of emotional intelligence. Emotional Intelligence originates from social intelligence theory and was popularised by the work of Goleman (1995). It is measured by EQ (emotional intelligence quotient) focusing on attitudes, behaviour and character, differing from IQ (intelligence quotient) that measures knowledge and skills. Belsten (2003) suggested EQ contributes between 27-45% job success, with most successful people having high EQ. Self-awareness is a key concept in emotional intelligence (Freshwater and Stickley, 2004, Akerjordet and Severinsson, 2008) having the ability to perceive emotions, manage emotions and respond appropriately. Pisanos (2011) recognised that establishing personal self-awareness led to better social awareness and relationship establishment, evident in any workplace but considered here in nursing. Emotional intelligence plays a significant role in productivity, teamwork and job satisfaction of nurses in any work environment that is demonstrated in the literature (Harper and Jones-Shenk, 2012). It is influenced by nurses' personal goals, experience in the profession and their workload which will now be explored.

Emotional Intelligence has predominantly been studied in relation to nurse leadership with little research focused on its value in clinical practice. While leadership style and effectiveness strongly contribute to the culture and effectiveness of the organisation (Crowne *et al.*, 2016), understanding the relevance of emotional intelligence in clinical practice would give further insight in the present study. Harper and Jones-Schenk (2012) identified in their primary research measuring the EQ of staff nurses that were so-called 'successful' staff

nurses (as deemed thus by their supervisors) had higher than average EQ scores. They found a negative correlation between age and empathy, indicating that older nurses tend to score lower on the empathy subscale. This was a small study ($n=42$) and further, larger scale research is needed to confirm any correlation between age and empathy. This is significant because many studies focus on the experience of students or nurses at the beginning of their career, leaving a gap in evidence regarding emotional intelligence and experience. Crowne *et al.* (2016) suggest a need for more research on professional development activities aimed at enhancing emotional intelligence, measuring it as an outcome.

McQueens' (2004) literature review of emotional labour and emotional intelligence suggested that there is a link between emotional intelligence and emotional labour, which positively influences the quality of nursing care. She highlighted that the higher their emotional intelligence, the more likely the nurse is to engage in emotional labour and seek connection with patients, whilst recognising the need for more research to corroborate this. McQueens' position is supported by Vilelas and Diogo (2014) who found that, for nurses who effectively manage their own emotions, engaging in emotional labour can result in 'therapeutic intentionality' (p148) leading to personal growth, heightened well-being, the relief of suffering and a positive transforming emotional experience. Perry (2008) recognised that when nurses had these attributes they translated into practice. She examined why exemplary oncology nurses avoid compassion fatigue in her phenomenological study and although she does not refer to the term emotional intelligence, found that her participants shared core nursing values, took a positive attitude and had an underlying value of altruism toward their work. It is these attributes that enabled them to see oncology nursing as a chance to make a significant difference in an individual's life at a difficult time rather than a depressing, physically and emotionally exhausting place to work.

However, it is clear from wider reading (Leary and Punshon, 2019, Bunting, 2020) that no amount of positive attitude can detract from organisational constraints of short staffing

leading to increased workloads. This creates pressures that will not be mitigated by emotional intelligence, although Aljarboa *et al.* (2022) recognised a correlation between emotional intelligence and resilience in the COVID pandemic, noting those with a higher emotional intelligence were more able to support others. However, there is no evidence that this is sustainable. Dall'Ora *et al.* (2020), exploring the precedents and antecedents for burnout in nursing in their systematic review cited high workload at the top of the list with inadequate staffing levels, negative team relationships and high time pressures as well as many other factors. This is supported by Pan *et al.*'s (2023) study which correlated burnout with workload where they demonstrated burnout rose and fell with waves of COVID peaks in the pandemic. Therefore, the imperative for safe staffing levels (Leary and Punshon, 2019) must remain central when addressing organisational constraints that contribute to burnout, low morale and consequently poor patient care.

This discussion of emotional intelligence concludes it is an important, under-researched contributing factor for nurses when engaging with emotional labour (as bearing witness to distress), to have meaningful engagement with their patients and colleagues and experience fulfilment, especially when the antecedents of teamwork, connecting with patients and space to process are present. It is a significant factor in nurses' experience of emotional labour which, with the findings from the present study, suggest current understanding of emotional labour should be revisited.

7.7 Revisiting emotional labour with a historical context

The original understanding of the concept of emotional labour was formulated in the 1960s and has not progressed in mainstream literature since the 1990s. I suggest that current understandings of emotional labour are framed by four key historical issues. These are second wave feminism, recognition of the emotional cost of nursing by Isabel Menzies', Nicky James's (1992) application of Arlie Hochschild's work to nursing, and the professionalisation of nursing taking on 'male models' (Rafferty 1996) rather than reflecting

the complexity of nursing, these issues are summarised in table 5. These factors remain relevant today and reinforce the belief that emotional work in nursing is an entirely a costly, negative aspect of care that depletes the nurse, with little recognition of the privilege and fulfilment of providing care. Each issue will be explored before offering a revised understanding of emotional labour.

Table 8. Summary of components that shape current understanding of emotional labour

Historical Issue	Date	Synopsis of issue
Second wave Feminism	1960s	focus on women's emancipation from domestic work including care responsibilities
Isabel Menzies identification of task orientation in nursing	1960	focus on the emotional cost of nursing leading to task orientation in an attempt to detach nurses from this work
Nicky James (1989) seminal work on emotional labour in nursing	1989	application of Arlie Hochschild's work to nursing practice, identifying the personal cost of emotional labour by masking true feelings

Drive for professionalisation of Nursing	1990s	Education establishments emulating medical model rather than reflecting the complexity of nursing

The second wave of feminism challenged the convention that the woman's place is in the home as a wife and mother, with little choice other than to conform to these roles (de Beauvoir, 1953, Friedan, 1963). Socialist/Marxist theories shone a light on the real and unpaid work of women as a consequence of capitalist exploitation of the proletariat, explored by Delphy (1970). She maintained that housework and childcare was deemed by men as "neither labour nor production" (p174), suggesting it is "a hobby, a vocation, a proof of love, a character trait; in brief anything and everything except work" (p176). Melchior (2004) argued that the second wave was mirrored in nursing. It was highlighted by the subjugation of women and devaluing of women's work that translated to a lack of status and power for nurses. Coburn (1974) recognised that in a feminine occupation such as nursing with an emphasis on service, duty, subordination to the male hierarchy and self-sacrificing commitment was bound to be poorly paid and granted little status, given the myth about male superiority. Coburn wrote in her book entitled "I See and Am Silent":

"...It was hardly necessary to justify low wages for nurses when their work was considered a public service and similar to unpaid work at home"

(Coburn, 1974, p155)

This continued devaluation of women's work in a male world was recognised by Reverby (1987) who identified the challenge for nurses. This is summarised by Melchior (2004):

“Nursing is based on caring not curing so although nurses are respected for caring, they are not compensated monetarily or through the acquisition of power or status for that caring. Yet if they complain, they are accused of not caring-thus, the dilemma”

(Melchior 2004, p346-347)

Second wave feminism highlighted the unpaid emotional labour of women both in the home and workplace. It revealed what was perceived as the oppression of women which reinforced it as a concept defined by burden and cost which was recognised in nursing by Menzies (1960).

Isabel Menzies's (1960) seminal work studying hospital life provided a clear and challenging view of the nature of nursing work. She identified the stress and anxiety of emotional nursing work as the cause of over 30% of students quitting before they finished their training (the proportion is very similar today, in 2019 attrition rates were 24% (The Health Foundation, 2019). This led senior nurses and management to advocate that nurses distance themselves from their work by taking a task orientated approach to care, protecting them from being exposed to the emotional labour of nursing. Menzies' work went on to inform a stream of work that shifted away from task orientation, to focus on therapeutic care influencing how nurses are educated and how healthcare is provided today (Tutton and Langstaff, 2014). Identification of emotional labour as an aspect of nursing care that leads to burnout is a legacy from this work that influenced James' (1992).

As I have explored, Nicky James (1989) was one of the first to use the term emotional labour in nursing. She applied the work of Arlie Hochschild (1979) to nursing, identifying how feelings are used within the work environment as a form of labour. Pam Smith concurred with James' position also writing extensively about emotional labour (Smith 1992). Although there have been studies since that recognise joy within emotional labour (Perry, 2002, Naef, 2006, Tutton, Seers and Langstaff 2008, Hilliard and O'Neil 2009, Larsson Gerdin, Hellzen and Rising-Holmstrom, 2021) the legacy that emotional labour is a negative experience that nurses need to be protected from because it is detrimental to those that engage in it still

endures today (Wentzel and Brysiewicz 2014, Mauno *et al.*, 2015, Jagiasi *et al.*, 2021, Nugent, Donohue and Higgins 2022). The tacit nature of emotional labour in nursing (Gray, 2009) can be understood by the drive to professionalise nursing.

From the 1960s there was a drive to professionalise nursing. The move within nursing was to develop knowledge and skills to keep pace with the technological healthcare system as well as to adopt a patient focused model of care, prioritising continuity of care and away from the task orientated, ritualistic care and depersonalization identified by Menzies in the 1960s. Rafferty (1996) highlighted the limitations, primarily in nursing education of adopting 'male models' that aim to establish criteria for professionalism by mirroring medicine rather than recognising the social complexity of nursing experience. Rafferty suggests policy makers in nurse education borrowed ideas developed by groups and institutions they perceived as being already successful. As a female dominated profession, nursing does not fit easily into the traditional mould within which archetypal professions have been cast. American nursing is organised autonomously, whereas British nurses forged alliances with medicine, which already had position and prestige. Because nursing provides the necessary support for medicine to maintain its dominance, it thereby perpetuates the subordination of nursing to medicine. Alignment with the medical model inevitably limits understanding and the nursing experience of emotional labour, therefore focusing on its cost and burden. In borrowing knowledge from other disciplines in the pursuit of a biopsychosocial approach to care (Theodosius, 2008) the complexity of this aspect of nursing is neither understood or celebrated. The current focus on cost-effectiveness by giving fundamental care over to unqualified personnel and taking on medical tasks makes close nurse-patient relationships an unlikely reality (Theodosius, 2008).

Consideration of these historical factors leads us to blur the boundaries of what emotional labour represents rather than how it is experienced. Its representation as invisible women's work, demanding and challenging yet integral in the nursing role causes us to see it as a burden. Yet evidence from the present study suggests it was not engaging in emotional

labour that was a burden or challenging for the participant CRNSs, it was not have the space to process, or support from their team that compounded the challenge. When these were in place, CRNSs recognised that this work was a privilege, it had meaning and purpose and fulfilled their identity as nurses. These findings have implications, which are relevant beyond community respiratory nursing have implications for clinical practice, research and education which will now be discussed.

7.8 A new understanding of emotional labour

The findings of this study suggest that it is time to present a new understanding of emotional labour that better reflects its complexity. Participants revealed that emotional labour illustrated as bearing witness to the distress of breathlessness, is not a binary experience but one that is nuanced in that it can be both challenging whilst feeling fulfilling and privileged. Therefore the 'labour' could be replaced with 'connection' demonstrating the engagement without the connotation of hard work and burden.

The experience of emotional labour, or connection for a nurse is shaped by their emotional intelligence, reflecting their dasein which impacts the relationship with the patient, by their environment that is influenced by workload, staffing levels and leadership priorities.

Therefore, rather than being protected from emotional connection, nurses should be supported to fully engage with authenticity. It is in attending to the human experience of nursing that an empathic relation between nurse and patient is revealed. It also begins to fill some of the gaps of understanding when exploring care of people with breathlessness and the disconnect between patient experience and therapeutic care. The conclusions of the study, focused on a new understanding of emotional labour will now be presented.

7.9 Conclusions and recommendations from the study

Table 6 outlines how the conclusions regarding emotional connection and fulfilment from this project can be applied to practice, but there are also specific findings for CRNS practice, and these will now be explored.

Supporting nurses to engage in emotional connection shifts the focus away from the narrative of avoiding burnout, compassion fatigue and gaining resilience; all terms regularly used (Perry 2008, Jackson *et al.* 2012, Cope, Jones and Hendricks, 2016, Dall'Ora *et al.* 2020, Roberts *et al.*, 2021, Pan *et al.* 2023) instead of celebrating the personal and professional benefits of being fulfilled as a nurse. This semantic shift to express the positivity of nursing is important in management when addressing the recruitment and retention of

Table 9. Summary of implications of research findings for clinical practice, research, nurse education and management

Application of research findings	Teamwork	Space to Process	Connecting with patients
Research: gaps in existing knowledge	Established body of knowledge of the benefits of teamwork in clinical practice but suggest the use of case study and mixed methods studies to highlight staff wellbeing, retention, productivity and patient satisfaction as outcome measures of cohesive teamwork	Research that identifies the benefits/challenges of 1:1 supervision versus group supervision Address issue space to process as a lone worker (community nursing) to improve support networks Further research on emotional intelligence and its connection with outcomes of care and wellbeing of nurses	Further HP research focused on experience to reveal new understandings. Development of dependency and capacity tools that capture complexity of nursing work Development of digital technology to reduce workload
Clinical Practice: requirements to support nurses to be fulfilled	Daily capacity meetings for team awareness of everyone's workload	Clinical supervision, Schwartz rounds, informal opportunities for reflection	Manageable workloads defined by dependency tools; use of digital technology where relevant

	Away days, face to face team meetings (as opposed to video platform meetings)		to reduce workload Confidence of all nurses to engage with emotional connection as a requirement of their role regardless of speciality
Nurse Education of undergraduate and clinical nurses: focus of learning	Include knowledge of the value of teamwork in wellbeing courses for undergraduate and qualified nurses	Train more clinical supervisors so that all nurses can have access to Clinical Supervision Identify emotional intelligence as a concept for awareness for personal and professional wellbeing	Embed understanding of the personal and professional value of emotional connection, with awareness of the antecedents for fulfilment Courses that focus on advanced communication skills, important conversations regardless of specialty Courses that specifically focus on symptom management of breathlessness
Management: recruitment and retention of nurses	Focus on the value of teamwork prioritising team building opportunities	Reinforce commitment to protected time for clinical supervision as a mandatory requirement	Exemplars of nurses having emotional connection with patients in recruitment campaigns

nurses. This is particularly challenging at the present time with over 50,000 vacant nurse posts and rising demand for health care (Health and social care committee, 2022). Nurses cite workload pressure, burnout and lack of support (Chamanga *et al.*, 2020) as some of the reasons for leaving nursing but the same research highlighted that job satisfaction, teamwork, direct patient care and fulfilment as reasons nurses stay in clinical practice, supporting the findings of the present study. The challenges of recruitment and retention are the biggest threat currently facing nursing and without safe staffing levels and workforce planning it is difficult to effect any change in nursing. Focus on the fulfilment and privilege of nursing working in a team, having meaningful engagement with patients and the support and space to process could be the central theme of a recruitment campaign when encouraging people to consider nursing as a career. Equally, when considering retention of clinicians in practice; a focus on these aspects to ensure nurses have space to process, that they have accessibility to clinical supervision and Schwartz rounds⁵. Evidence from the first evaluation of Schwartz rounds in the UK (Flanagan *et al.*, 2020) concluded that healthcare staff valued these rounds as a space to reflect on their work, to listen and connect with their colleagues. Both Clinical Supervision and Schwartz rounds can be an opportunity for nurses to debrief, give and receive support in a formal setting and reflect on the practice of themselves and others. However, these activities do not address the situational challenges for CRNSs as lone workers that were highlighted in the study; further research that considers practical solutions to explore this aspect of the role may address this issue.

Ensuring there is team support by daily capacity meetings so everyone is aware of each other's workload will go some way to recognise the importance of teamwork when striving for fulfilment. Prioritising team meetings that are face to face or at least adopt a hybrid use of

⁵ Schwartz rounds were brought to the UK in 2009 from the Schwartz centre for compassionate healthcare, USA. They consist of open meetings that enable healthcare staff to reflect on the emotional challenges of their work in a safe and confidential space

video platforms will enable teams to connect together and building opportunities for away days into the work schedule could prioritise mutual support, trust and understanding to build the team. Ensuring workloads are manageable for each nurse will remain a challenge as long as services are short staffed, and nurses continue to leave the profession. Workloads are rarely objectively measured as there are few dependency tools for clinical use that effectively demonstrate dependency and capacity in nursing teams and capture the complexity of nursing work (Brady *et al.* 2007, Wort *et al.*, 2015). The use of digital technology, where relevant, can be adopted to reduce workload. Telehealth⁶ in Community Respiratory Nursing can support clinical practice and is well received by patients (Gale and Sultan, 2013) although Taylor *et al.* (2015) recognises that clinical 'buy-in' can be an obstacle to successful implementation. Therefore, research and implementation that puts nurses front and centre of decision making will result in their meaningful engagement in adopting new ways of managing workload. When workload is manageable, nurses feel more able to reflect on practice and engage with patients involving emotional connection, offering opportunities for fulfilment.

Acceptance that emotional labour is a burden and cost to nurses is politically driven. It would be better understood through research that examines nurses' experience of it. Research that focuses on the experience of nurses providing clinical care revealing the complexity of care will further understanding of emotional connection. In the context of the recruitment and retention crisis in nursing, this research could contribute to strategic priority setting which incorporate the antecedents of fulfilment of nurses in clinical practice. This particularly highlights the value of HP research, examining experience with openness and wonder rather than research driven by preconceived ideas that focus on hypotheses or fixed ideas.

Research that builds on the existing body of knowledge about the benefits of teamwork in clinical practice could use case studies or mixed methods and identify the fulfilment of

⁶ Telehealth is the digital monitoring of patient health through telecommunications installed in the home

participant nurses as an outcome of the research. Prioritising more research that identifies the benefits and challenges of group and individual clinical supervision will deepen understanding of the needs of clinical nurses to meaningfully provide them with space to process. This could address the issue of lone working for community nurses, especially when dealing with challenging visits to understand how 'space to process' could be incorporated into their day. While there is some evidence about the role of emotional intelligence in emotional labour and fulfilment, more research is needed to understand how it can be enhanced in clinical practice using it as an outcome measure when assessing the value of professional learning and patient satisfaction.

7.9.1 CRNS implications for practice

Caring for people with breathlessness, especially at the end stage of disease is an essential part of caring for people with respiratory disease. The study reveals that the experience of caring is profound for CRNSs and their thrownness will have a direct impact on the care they give. Many of the nurses spoke of the challenge of "not doing anything" for their patients because they could not offer further practical solutions (Hilary, Janet). They did not recognise 'being-with' as an active role in care. Equipping CRNSs with the skills to support people with breathlessness through the suggestions in Table 6, will begin to address some of the existential challenges for CRNSs, this may lead to improved outcomes for this patient group, reducing the costs of acute care by providing person-centred care. This may enable CRNSs to feel empowered and fulfilled in their role and result in better service delivery.

The focus of specialist nurses is often on practical, disease focused skills but this study, considering lived experience of CRNSs, reveals that equal priority should be given to advanced communication skills, understanding of emotional intelligence and building team dynamics as just a few ideas of supporting CRNSs to engage with emotional connection.

7.10 Conclusion

The discussion has explored the complexity of care when bearing witness to distress as breathlessness revealed through the analysis. In recognising both the challenge and fulfilment for participant CRNSs of the experience of supporting people with breathlessness, new understanding has emerged. I have considered the antecedents identified as ways to fulfilment, the impact of emotional intelligence and challenged current understanding of emotional labour to suggest new understanding, framed within the term emotional connection. This deeper insight sheds light on the complexity of nursing care that can be shared beyond community respiratory nursing. The findings and recommendations of this study have been summarised demonstrating the opportunities to develop practice, ending with a particular focus on the role of the CRNS.

I will now outline final thoughts from the project discussing the strengths and limitations of the study and conclude with how this research project has changed me.

Chapter 8: Final thoughts and Conclusions

Nature's music is never over; her silences are
pauses, not conclusions.

Mary Webb, 1927

8.1 Introduction

In this chapter I reflect on the strengths and limitations of the study and consider my position as a novice researcher undertaking an HP study. I outline my reflexive approach to this research and evidence how I have used rigour throughout the study. I reflect on how this project has changed me, identifying both personal and professional impacts, before concluding the project.

8.2 Strengths and Limitations of the study

8.2.1 Strengths

There are several strengths of this research project that include phrasing of the research question, the three-stage process of analysis used, the focus of it being clinician-led research and its wider application beyond respiratory nursing. Each of these will be discussed.

Reading around the subject and approaches to research, this research differs significantly from other research studies regarding experience of care because it approached the subject of nurses' experience of breathlessness with open curiosity. I simply asked the question "what is your experience?" Looking at the literature I can see that related research focused on a particular perspective: "what is your experience of burnout?" (Voultos *et al.*, 2020), or "how do you get fulfilment from your work?" (Perry 2007). Both of these studies take

participants down a particular route to retrieve examples of experiences that take one view or another. By asking an open question, participants answered from their own perspective, sharing their individual experiences that led to reveal the complexity of the fulfilment, but also the challenge of supporting people with breathlessness.

Modifying Crowther and Thomsons' (2020) analysis to my own three stages of HP analysis was a gateway to revealing this complexity. I recognise that each of these stages revealed understanding that collectively contributed to the new knowledge. Crafting stories was integral to the interpretative process and provided glimpses of the phenomenon that other forms of data analysis may overlook (Crowther *et al.* 2016). Observing the crafted stories through the lens of the Heideggerian notions embeds philosophical understanding of the data within this research, bringing ontological insight to the experiences shared by the participants.

The phenomenon of fulfilment was revealed through attunement, observed within each interview video, crafted story, commentary and reflection. It was the reflexive, interpretive approach of HP methodology that enabled this unconcealment which would not have been revealed had I used a different methodology, or a computer platform designed to assist with revealing themes, it is not intuitive. This feels an important acknowledgement to make and is a sentiment shared by Taylor (2022).

This is clinician led research; the research question comes from a place of clinical experience and curiosity that seeks new knowledge for clinical practice. Addressing this question which might appear to be quite niche to others not in the field of respiratory nursing has highlighted an unexplored area of research that reveals valuable insight into the experience of participants.

This research could extend beyond the field of respiratory nursing as it could be applied to nurses bearing witness to forms of distress other than breathlessness and challenges accepted assumptions around emotional labour.

8.2.2 Limitations

The most pertinent methodological challenge as a novice researcher in using interpretive phenomenology was to embed an understanding of philosophy. Smythe and Spence (2019) identify the challenge of “reading Heidegger”, in understanding what is being said in order to make the interpretive leap. They suggest that journeying in a hope of understanding. This challenge was met by revisiting much of the published literature, undertaking an online HP course (Hermeneutic Phenomenology Course, 2021) and partaking in a Heidegger Reading Group. However, I do recognise my understanding will never be complete. Being a novice researcher impacted my interview technique, this resulted in the transcripts being a superficial example of HP interviewing, evident when seeking evidence for analysis. I did the majority of the interviews before completing the online HP course, following which I developed better interview skills with an increased knowledge of HP. In many of the interviews I was chatty and informal with the participants. I could have picked up on cues that were clear to me when listening back to the interview recordings by using more incomplete sentences, leaving longer silences for the participant to fill and returning them more to their story.

Reflecting on my recruitment technique, I can see that recruiting participants via Twitter and the ARNS email Newsletter immediately restricted the purposive sample to those who were Twitter followers with a professional interest and those engaged with professional development as members of ARNS. These are more likely to be committed, motivated nurses, and I am aware that the participants may not be an entirely representative sample of the views of CRNSs. However, at the time of recruitment this was the most viable way, as recruitment was limited to virtual spaces with conferences going online and all face to face meetings prohibited. It still enabled me to have a purposive sample that was entirely voluntary but is nonetheless important to consider this limitation.

A further limitation was that participants were aware of the questions that would be asked in the interview from the Participant Information Sheet (Appendix 1) so had time to prepare and choose which experiences to disclose. Alvesson (2003) and Qu and Dumay (2011) suggested that this enables participants to offer themselves as more mobilised in situations rather than give a more mundane, factual account but it did also enable participants to give thoughtful, considered accounts of their experiences. This was however the requirement following my ethics application.

8.3 Reflexivity in hermeneutic phenomenology

Unlike Husserl, Heidegger (1962), suggested our human essence, the way we make sense of things is our fundamental ontology and we can never suspend what we know. He proposed that our lifeworld (the world in which we live in), intentionality (direct awareness of being in the world) and thrownness (our situation in the world) mean there is always a context to *dasein*, we cannot avoid these aspects of who we are when considering meaning and understanding. As a researcher, reflexivity demonstrates the dialectic between my pre-understandings coming into the research and the research process. As Giorgi (1994) stated “nothing can be accomplished without this subjectivity” (p205) because each person will perceive any given phenomenon in a different way bringing to bear their own life experience, specific understandings and historical background (Heidegger, 1962). Rather than trying to abolish the researcher’s presence in research, the use of reflexivity demonstrates an audit trail of decision making and documents the researcher’s unique contribution in interpretation of data (Finlay, 2002, Tobin and Begley, 2004). This is a critical component when demonstrating academic rigour in this research project as well as identifying the “*moral integrity*” of the researcher (Kvale, 1996, p281). Reflexivity and Reflection are a continuum where reflexivity is

“the capacity of the researcher to acknowledge how their own experiences and contexts (which might be fluid and changing) inform the processes of inquiry. Awareness of how our

thoughts, feelings, culture, environment and social and personal history informs the research process”.

Etherington, 2004 p31-32

It is different from reflection which can be understood as

“the ability to reflect on one’s actions with an awareness of an implicit knowledge base, informing us to engage in a process of continuous learning”

(Schon, 1983)

In research terms this can be translated as

“thoughtful, self-aware analysis of the intersubjective dynamics between the researcher and researched”

(Finlay and Gough, 2003 p ix)

In an HP project the process of reflection and reflexive analysis starts from conception of the research. As the researcher collecting, selecting and interpreting the data, I recognised my position influenced the decisions made and the nature of the analysis.

Van Manen observes that:

“the problem with phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much”

(van Manen, 1997, p46).

The reflexive process explicating pre-understandings is temporal, changing over time with reading and experiences to develop thoughts and ideas. Therefore, pre-understandings also include mid understandings and post understanding, demonstrating the dynamic HP process. I have reflected on my own relationship to the project; my motivations, assumptions

and interests identifying forces that might skew the research in a particular direction. These accounts are documented throughout chapter 5 and in Appendix 8 but are also referred to throughout the study. Field notes written following the trial interview conducted between a member of the supervisory team and myself, the 2 pilot interviews and the 12 research interviews contribute to my reflexive diary. Reflexive analysis exposes how the outcome of data collection was impacted by how the research relationship evolved; at times challenging my beliefs about breathlessness, other times feeling positive in affirming shared beliefs with the participants.

8.4 Rigour

Morse *et al.* (2002) suggested rigour is vital in order to have confidence in the findings of a research study, and without this research is worthless. This has been adopted from positivist research where the gold standard is to demonstrate rigid methodological and easily replicable frameworks. Rigour and trustworthiness are used interchangeably in literature to describe the process of assessing the quality of qualitative based research. The etymology of rigour stems from old French and Latin words to mean 'strength', 'firmness' and 'exactness'. Trustworthiness stems from old Norse and Proto-Germanic terms such as faithlessness, 'confidence' and 'fidelity' (Thomson and Crowther, 2022). Exploration of these terms demonstrate they are the antithesis to HP study yet are demonstrations of quality of good research. Thomson and Crowther (2022) argue that new terms like 'integrity' and 'credibility' are better suited to HP research reflecting honesty, believability and wholeness as markers of quality. These terms align more with the hermeneutic paradigm of being open to ponder and reflect and show vulnerability. However, for the purpose of this thesis and in order to demonstrate rigour in this research project the 4 criteria for trustworthiness in qualitative research will be demonstrated (Lincoln and Guba, 1985). These are credibility, transferability, dependability and confirmability.

Credibility, aligned with the truth-based value can arguably only be judged by the participants or peer group from which the participants originate (Cypress, 2017). It aligns with de Witt and Ploeg's notion of resonance and the 'phenomenological nod'. Credibility is demonstrated when data is presented in a way to 'show' and not 'tell' the reader (Smythe *et al.*, 2008), to demonstrate meaning from the data, showing the possibilities rather than closing down thinking. Credibility is therefore demonstrated by how the thesis is written, presenting ontological understanding that enables the reader to "think-along" as new understanding unfolds. Credibility occurs when others connect with what is shared, demonstrated in peer reviewed publications that have resulted from this research (Speakman *et al.*, 2021a) and presentations to the CRN community (Speakman, 2021b). This was achieved by drawing from original data generated from the participants from Crafted Stories and direct quotes.

Transferability is the applicability of the research. It is similar to generalisability (used in quantitative based studies) in which research findings, based on a population sample are applied to the population at large. However, transferability, while similar in its aim of making wider inferences, does not involve broad claims, inviting the reader to make connections. Demonstrating the socio-demographic, wider cultural and political context in which the stories were captured, situates participants' experiences outside of the study situation, and resonates to wider contexts. Although this study is focused on the CRN experience, it could reflect similar perspectives in other community nurse roles and beyond community nursing when considering witness to distress. Transferability can be demonstrated when varying perspectives are offered in the hope to provide a non-objectifying, non-theorising academic prose that is plausible when shared with others (Mason, 2002). This study has sought to do this, especially when expanding the discussion around nursing and emotional labour. Evidence that decision making extends to the supervisory team reflects wider voices in the interpretation as well as those of the participants showing co-construction.

Dependability is the consistency criteria that demonstrates how decisions are made. It establishes the research findings are consistent and repeatable. This is challenging where interpretations are made, in HP the “aha” moments to explicitly show how the interpretative leap was made. Dependability relies on clear evidence of methodological approach used and how it has been undertaken. Lincoln and Guba (1985) suggested that without comprehensive methodological documentation in which all inquiry decisions are identified, explicated and supported, an accurate assessment of the dependability of the study cannot be made. Crowther and Thomson (2022) recognised that within HP, authors have different styles which should be honoured; dependability cannot be demonstrated as a linear formula but does need to show readers how the phenomenon was revealed. An audit trail detailing early emergent issues and qualities that were important throughout this project is evident in the analysis (chapter 5), justifying decisions that have been made. A reflexive diary, started from conception of this project, is an integral part of demonstrating thoughts around the decisions that were made and that evolved over time. While the methodology can be clearly explained, the to-and-fro of the analytic process is demonstrated in the reflexive diary. Crowther and Thomson (2022) recognised that a key goal of HP research is to ‘show’ the reader how interpretations that were always-already-there, waiting to be discovered. This was achieved by using participant data to show and not tell, blended with philosophical insights in part 2 of the analysis (chapter 5).

Confirmability is the neutrality criteria that demonstrates the degree to which findings are the product of the focus of the inquiry and not based on the biases of the researcher. It is similar to credibility in terms of demonstrating how interpretations were grounded in the data and is especially evident in parts 2 and 3 of the analysis. However, a key feature of confirmability is reflexivity. HP aims to unconceal, finding something that is hidden, generating new interpretations that are a fusion of horizons rather than just the interpretations of the researcher in the situation. This is demonstrated with clear reflexivity throughout the project, situating myself, the researcher at the start of the project, interweaving reflexivity in the

findings and summarising at the end as to how thinking has evolved. Smythe and Spence (2012) suggest that for nearly all HP researchers, their research resonates with them personally and researchers gravitate towards HP studies due to professional experience with the phenomenon of interest. They conclude that fore-conception; a sense of what our interpretations will be is “the most dangerous aspect of understanding” (Smythe and Spence, 2012, p16). Heidegger warned against the vicious circle whereby we interpret based on what we already know, swayed by ‘the They’ of the everyday understanding of the natural attitude, covering over the understanding of dasein.

Crowther and Thomson (2022) acknowledged the importance of a pre-understandings interview at the start of the project, providing an invaluable opportunity to reflect on the reasons for undertaking the study, as well as conscious and unconscious pre-understandings. This was done by one of the supervisory team asking me (as the researcher) the in-depth questions intended for my research participants. This not only provided the opportunity to acknowledge my own answers to the questions, but empathy for the participants revisiting what were often challenging, sometimes emotional experiences that enabled deep reflection and catharsis as a result of the process. I was enlightened by my pre-reflective ways of knowing, recognising my own position and as van Manen (1997) calls for; to engage in an openness that revealed attunement to the phenomenon.

8.5 Reflections on how my research has changed me

Reading Heidegger has remained a challenge throughout the doctoral journey, but the plethora of texts and commentaries that are available that guide and support the reader, have been invaluable in having the confidence to navigate Being and Time. Smythe (2011) suggests that some people are naturally attuned to phenomenology, comfortable with the “free flowing let-the-thoughts come nature of phenomenology” (p37), this encouraged me to pursue my desire to use HP, despite the challenges because I was happy to trust the

process. Using HP for this research and understanding Heidegger's notions has enabled me to recognise the complexity and uniqueness of each human being be it staff member, patient, friend or family. Their dasein, shaped by lived experience, historicity and thrownness has helped me to spend time knowing and understanding the individual in order to identify how best to help them in a clinical setting and not to assume anything. This might sound obvious, but sometimes in specialist nursing, when people share the same diagnosis or symptom there can be assumptions made about the disease process and people's needs rather than looking at the individual, hearing their lived experience and understanding individuals' expectations that are hugely variable.

My research findings, taking me from breathlessness to the complexity of emotional labour and fulfilment were a revelation to me and this was not an outcome I had considered when starting this research. Yet I can see with such clarity that meaningful engagement with others is why many of us are nurses and should be supported and celebrated. The findings have encouraged me to embrace challenging clinical situations, offering support to colleagues to explore their feelings and emotions by recognising the importance of teamwork, identifying opportunities for team building and meeting together. I also prioritise group clinical supervision and seek out one-to-one conversations with colleagues who I know are supporting challenging patients and facilitating end of life care. It has given me confidence to address psycho-social, existential challenges with patients, recognising the importance of their lived experience both past and present and their own relationship with being-toward-death.

I chose HP because I felt it would best reflect the lived experiences of the participants, but I was very challenged by doing the methodology justice at the outset. I am very grateful for the online HP course (Uclan and AUT, 2021). This course enabled my confidence and understanding of the methodology to grow. I met others who were also doing research and the peer support we received from each other was sustaining when working through our research projects. I can see that this methodology is really valuable for clinical practice,

because in focusing on experience as the primary focus, there are opportunities to explore insights and gain deeper understandings that might be lost with other methodologies.

8.6 Conclusion

The aim of this hermeneutic phenomenological study was to explore the experience of CRNSs of supporting people with breathlessness to reveal new understanding of this unexplored area of research. This is important because breathlessness is challenging to experience and difficult to witness, yet it is a common, pervasive symptom for most people with respiratory disease, especially those at the end of life. It is therefore an aspect of care for CRNSs that is integral to their role. After exploring the clinical and broader literature regarding breathlessness and the experience of caring, the rationale for the choice of methodology was explored. I introduced a brief philosophical overview of Heidegger's key notions that were used to analyse the data and outlined the methods of the study, describing recruitment and interviewing of twelve CRNSs regarding their experiences of supporting people with breathlessness. I analysed the data in three stages: crafting stories from the data, which was integral to the interpretive process, revealing the story of the experience shared by participants, analysing the crafted stories using the Heideggerian notions and analysis through attunement of the interviews. Reflexive accounts of my own positionality in the study offered insights into how my thinking has impacted decision making within the project.

Analysis revealed that while participants did indeed find bearing witness to the distress of breathlessness difficult, feeling both personally and professionally challenged, they also felt fulfilled and privileged through the meaningful engagement they shared with patients. This nuance of challenge and fulfilment led me to examine current knowledge and understanding of emotional labour. Emotional labour is often associated with burnout and compassion fatigue for nurses and has historically been considered as something to protect nurses, and

women from. Yet this research suggests that when the antecedents of teamwork, connection with patients and 'space to process' are in place; emotional labour is an opportunity for fulfilment. I suggest emotional labour is reframed as 'emotional connection' and nurses are in fact supported to seek this connection. Recommendations from this new understanding include more research regarding the antecedents to fulfilment, to enhance clinical practice for both specialist respiratory nurses and wider teams by addressing the three antecedents and to reflect this in nurse education. The positive approach to frame nursing as a profession where people can seek fulfilment, rather than prevent burning-out is an important semantic shift when tackling the challenge of recruiting nurses, given the national, and international shortage of nurses. However, this message will only resonate when the antecedents of teamwork, connection with patients and 'space to process' are committed to and managing unreasonable workloads and safe staffing levels are prioritised.

As an HP researcher, I am aware that I am only ever on the way to understanding and that understanding is not complete. Stories have multiple layers and multiple meanings (Gadamer, 2008) and when light is shed in one area to unconceal a phenomenon, another part is concealed. By bringing the phenomenon of fulfilment into the light I have revealed new ontological meaning yet there are other entities that will still be in the dark. I am aware there is not a single attunement and other researchers will have attuned to different phenomena within the same data. I understand this is the nature of HP research, aware there is no distinct end as there is still much regarding this phenomenon that is unthought and unsaid. However, through the experiences of others I have articulated a phenomenon that speaks of the celebration of human connection and that will resonate with other nurses.

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Appendices

Appendix 1



Dr Sue Schutz
Director of Studies
Faculty of Health and Life Sciences
Oxford Brookes University

28th July 2020

Dear Dr Schutz,

UREC Registration No: 201406 Speakman
Study Title: An exploration of the experiences of Community Respiratory Nurses supporting patients who are breathless

Thank you for the email of 26th July 2020 outlining the response to the points raised in my previous conditional approval letter regarding the PhD study of your research student, Lucy Speakman and attaching the revised documents. I am pleased to inform you that, on this basis, UREC is happy to grant full approval for this study.

The UREC approval period for the data collection phase of the study is two years from the date of this letter, so until 28th July 2022. If you need the approval to be extended please do contact me nearer the time of expiry.

Should the recruitment, methodology or data storage change from your original plans, or should any study participants experience adverse physical, psychological, social, legal or economic effects from the research, please inform me with full details as soon as possible.

Yours sincerely,

A handwritten signature in blue ink, appearing to read "S Quinton", with a long horizontal flourish extending to the right.

Dr Sarah Quinton
Chair of the University Research Ethics Committee

cc: Dr Dan Butcher, Supervisory Team
Mrs Lucy Speakman, Research Student
Ms Kellie Tune, Research Ethics Officer
Ms Jill Organ, Research Degrees Team

Appendix 2 Participant information Sheet

Study title: An exploration of the experiences of Community Respiratory Nurses supporting patients who are breathless

Invitation: You are invited to be part of a qualitative study exploring Community Respiratory Nurse Specialists (CRNS) experiences of supporting their patients who have difficulty breathing. This would involve a telephone interview that lasts 30-60 minutes to explore your thoughts and feelings when supporting people with breathlessness. Involvement is entirely voluntary and confidential.

What is the purpose of the study? People living with Advanced Respiratory Disease and difficult breathing (and those closest to them) have a poor quality of life. Increasingly difficult breathing can cause fear and anxiety for both patient and caregiver, so the CRNS is called upon to offer practical and emotional support and guidance. However, supporting patients with difficult to treat symptoms impacts the clinician. To witness difficult breathing is to witness distress. So, when a CRNS supports their patient, it is likely the nurse will be exposed to distress, which might have a personal emotional cost and influence the care they give. The nature of the support provided by CRNS to patients with difficult breathing will therefore be the subject of this project. Using interpretive phenomenology, the experiences of CRNS supporting patients with difficult breathing will be explored and the consequence for patient care. This is an unexplored area of research. The interpretations generated from the data will be used to provide guidance for core standards of support and education for CRNS. This will directly benefit patients who have difficult breathing by contributing to improvements in the care delivered.

Why have I been chosen? The study is focusing on the role of Community Respiratory Nurse Specialists in supporting patients with difficult breathing with a community caseload. This is because the community nursing role mostly involves long term support of patients, which is the focus of this study. Any nurse working within this remit will be eligible to take part in this study.

Do I have to take part? There is no obligation to take part in this study, your involvement is entirely voluntary. You can opt out of the study at any time up until the point of data analysis. If there are too many people interested in taking part in the study then individuals will be chosen from their geographical location, to get a spread of experience across Great Britain.

What will I have to do? You will be contacted within 2 weeks of receiving this information sheet. If you have any questions please contact the research team. If you agree to participate, a mutually convenient time for you and the researcher will be arranged for the telephone interview. On the day of the interview you will be asked to sign an electronic consent and email it back to the researcher prior to the interview. You will be asked about your experiences of supporting patients' breathlessness in your role as a CRNS, focusing on your own thoughts and feelings rather than the functional, practicalities of delivery of care. This will take between 30-60 mins and will be audio recorded.

What are the possible disadvantages and risks of taking part? You will be asked open, semi structured questions that ask you to recall a time you cared for someone who was breathless. This will be explored together with the researcher to understand how you felt in this situation, what happened clinically, personally or professionally. There is a chance this recalling of incidents might

prompt you to revisit challenging or emotional experiences. You can stop the interview at any time and will be sign posted to RCN/Unison and Occupational Health as appropriate. You should be aware

Appendix 2

that as a nurse, the researcher is bound by the NMC code and has a duty to report any clinical practice shared that might fall outside the code of conduct.

What if there is a problem? If there are any concerns, they can be raised with the chair of the Research Ethics Committee (details below).

Will my participation in the study be kept confidential? Yes, your participation will be kept confidential. Your data will be pseudonymised, this means your name will be replaced with another name. Data will be stored in a locked password protected computer on a google drive, only accessible to the research team.

What will happen to the results of the study? The study results will be written up as part of the researchers Professional Doctorate thesis. This will be submitted for publication and shared through conference presentations. The Clinical framework for core standards of support and education for CRNS will be disseminated via ARNS. You will be informed of all upcoming publications and conference presentations.

Who is organising and funding the research? This research is being carried out as part of a Professional Doctorate at Oxford Brookes University. The nurse researcher is funded by Oxford Health NHS Foundation Trust.

Who has reviewed the study? The study has been reviewed by the Oxford Brookes University and Faculty Ethics Committees as sponsors and insurers of the study

Further information and contact details:

Community Respiratory Nurse/Doctoral Student Lucy Speakman:

17004683@brookes.ac.uk Principle Investigator: Dr Sue Schutz seschutz@brookes.ac.uk

Second supervisor: Dr Dan Butcher dbutcher@brookes.ac.uk

Concerns about the conduct of the study contact university research ethics committee Sarah Quinton ethics@brookes.ac.uk

Thank you for your time.

Appendix 3: In-depth interview schedule

Introduction 5-10 mins

Can you tell me a bit about yourself and what brought you into community respiratory nursing?

Do you have any specialist interests within your role? Any courses studied?

How long have you been a community respiratory nurse?

Are you primarily a community nurse or do you have other roles (hospital/clinics/pulmonary rehabilitation)?

How many nurses work in your team?

Broad question 5-10 mins

What do you see as your role in helping patients manage their breathlessness?

What do you see as best practice for managing breathlessness?

Focused question 20 mins+

Can you tell me about a time you cared for someone who was very breathless?

How did you feel in this situation?

How did this experience affect you personally or professionally?

What clinical and emotional support is in place for you within your team? Do you think this is adequate?

How did this experience inform your future practice?

Follow up questions 5-10 mins

Do you think breathless management can be enhanced?

Are there opportunities or barriers to achieving this in your practice?

What do you think nurses specifically bring to supporting patients with breathlessness?

Do you have any other thoughts you would like to share regarding this subject?

What do you think the nurse role brings to supporting patients with breathlessness that is different to other health care professionals?

Appendix 4: Privacy notice for research participants



This privacy notice provides information on how Oxford Brookes University collects and uses your personal information when you take part in one of our research projects. Please refer to the research participant information sheet for further details about the study and what information will be collected about you and how it will be used.

Oxford Brookes University (OBU) will usually be the Data Controller of any data that you supply for this research. This means that we are responsible for looking after your information and using it properly. The exception to this is joint research projects where you would be informed on the participant information sheet as to the other partner institution or institutions. This means that they will make the decisions on how your data is used and for what reasons. You can contact the University's Information Management Team on 01865 485420 or email info.sec@brookes.ac.uk.

Why do we need your data?

Your data is being used to inform research about community respiratory nurses supporting patients with breathlessness. You have been identified as someone who might make a contribution because of your nursing role.

OBU's legal basis for collecting this data is:

- You are consenting to providing it to us; and / or,
- Processing is necessary for the performance of a task in the public interest such as research

If the university asks you for sensitive data such as; racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, data concerning health or sexual life, genetic/biometric data or criminal records OBU will use these data because:

- You have given OBU explicit consent to do so; and / or
- Processing is necessary for scientific or research in the public interest.

What type of data will Oxford Brookes University use?

The data gathered for this study is demographic information and from an interview conducted between researcher and participant.

Who will OBU share your data with?

OBU will not share your data with anyone

Third party processor Google services will be used for data hosting

Will OBU transfer my data outside of the UK?

No

What rights do I have regarding my data that OBU holds?

- You have the right to be informed about what data will be collected and how this will be used
- You have the right of access to your data
- You have the right to correct data if it is wrong
- You have the right to ask for your data to be deleted
- You have the right to restrict use of the data we hold about you
- You have the right to data portability
- You have the right to object to the university using your data
- You have rights in relation to using your data in automated decision making and profiling.

Where did OBU source my data from?

Data was sourced voluntarily from participants when consenting to this study

Are there any consequences of not providing the requested data?

There are no consequences of not providing data for this research. It is purely voluntary.

Will there be any automated decision making using my data?

There will be no use of automated decision making in scope of UK Data Protection and Privacy legislation."

How long will OBU keep your data?

In line with Oxford Brookes policies data generated in the course of research must be kept securely in paper or electronic form for a period of time in accordance with the research funder or University policy.

Who can I contact if I have concerns?

In the event of any questions about the research study, please contact the researchers in the first instance (contact details in the study participant information sheet). If you have any concerns about the way in which the study has been conducted, contact the Chair of the University

Research Ethics Committee at ethics@brookes.ac.uk. For further details about information security contact the Data Protection Officer at: brookesdpo@brookes.ac.uk or the Information Management team on info.sec@brookes.ac.uk

Appendix 5: Consent Form

Project Title: How do Community Respiratory Nurses attribute meaning to their experiences of supporting patients who are breathless?

Lucy Speakman, Professional Doctorate in Nursing Student at Oxford Brookes University

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.
3. I agree to take part in the above study.
4. I agree to the interview being audio recorded and transcribed
5. I agree to the use of anonymised quotes in publications
6. I agree that an anonymised data set, gathered for this study may be stored in a specialist data centre/repository relevant to this subject area for future research
7. I would like to receive a summary of this research, upon completion

Appendix 6: Poem She's Breathing by Alexandra Pârvan

A poem has been removed from this version of the thesis due to copyright restrictions. The full poem can be accessed here: <https://lifeofbreath.webspace.durham.ac.uk/shes-breathing-a-poem-by-alexandra-parvan/>

Appendix 7: Poem Contact II by Khadija Rouf

A poem has been removed from this version of the thesis due to copyright restrictions. The full poem can be accessed here: <https://www.bps.org.uk/psychologist/poems-nhs-best-poem-country-has-ever-written/>

Appendix 8: Brief biography of each candidate

At the time of data collection, Andrea had been a nurse for 28 years. She moved into community respiratory nursing 14 years ago following what was initially a short-term secondment from ITU for a newly started community respiratory service with her knowledge of interpreting blood gases for people prescribed home oxygen. She was a passionate nurse who communicated articulately her desire to care for her patients holistically. She was empathetic which enabled her to relate to her patient with humanity and deep caring. This was evident during the interview when she got tearful and upset, recounting her patient story.

At the time of data collection, Belinda, a colleague of Andrea, had been in her post for 15 years. She had a public health background which took her into health visiting. She had worked previously in respiratory disease management with paediatric asthma clinics before seeing adults “igniting her passion” for respiratory disease management. Belinda shared a lot of factual information about her role in her patient story and, despite prompting to share her own experience, was reluctant to talk about her own feelings. She spoke of breathlessness with a disease focus rather than lived experience. She often spoke of herself as third person “you do what you can” removing herself from the emotion of the patient's experience.

At the time of data collection, Carrie, in her 60's had been nursing for many years. She had been a community respiratory nurse for 11 years developing an interest in caring for people with COPD following a particular gentleman she cared for in a community hospital. She was the only participant of the 12 interviewed that I knew as a work colleague prior to interview.

This familiarity and comfort with each other might explain her incredible openness and honesty when answering my questions, probably more so than any of the other participants. She knew what my research was about so came into being a participant knowing I wanted to focus on experiences from a personal perspective, she gave me this which has provided me with a lot of rich data.

Deborah was another very experienced nurse. She has an interest in respiratory following a long career in critical care, intensive care and critical outreach. She had been in a strategic, less patient facing role as a matron in recent years and at the time of data collection, had been working part time in her current CRNS role for the last 4 years. Deborah shared a very practical account of the care she provided her patients; focusing a lot on oxygen and pharmacological management when referring to people with breathlessness. She did not share how this impacted her personally but having worked managerially, it was clear she appreciated the opportunity for meaningful patient connection.

Esther is a nurse with 40+ years' experience, contacted me as a result of snowballing from Andrea's and Belinda's interviews. She came to the role of CRNS following a long career in critical care nursing and was very honest that at the time of data collection, her current role was challenging for her because the skills required are so different to critical care nursing. Her views about the role were also very functional and her descriptors were around frustration with patients that would not listen or do what she felt was required. Esther's desire to avoid connecting with her patients was clear when she said that she did not feel it was helpful to get too close to her patients and was clear that she should remain within her professional role. This was the longest interview with over 17 sides of A4 to transcribe. Esther was reflective, open and honest, aware of the huge and differing challenge that community nursing presents in contrast to critical care. Through her patient story she

recognised her personal challenge of caring for people who are breathless because her role is less about “doing” and more about facilitating.

At the time of data collection, Fiona was a CRNS employed by a hospice to provide palliative care, it was a new role to her, having started during the pandemic. Her previous role was caring for people with lung cancer. With a focus on palliative care, Fiona clearly had a lot of expertise in caring for people with breathlessness and approached challenging clinical situations with confidence to help her patients. She also shared openly about the personal costs of this work for her. Fiona spoke of trying to balance her role as a mother of two preschool children, a wife and a nurse, she was reflective and very honest about her personal limitations and vulnerability coming to the job.

Gwen is another very experienced nurse, qualified for 27 years who has cared for respiratory patients throughout her career in the hospital, primary care and at the time of data collection, the community. She was in charge of a team of CRNSs who worked autonomously in a rural location. She had good knowledge of strategies for caring for people with breathlessness and recognised this as an important aspect of providing holistic care for respiratory patients. She was open and honest and deeply reflective, sharing her own thoughts and feelings regarding her experiences of caring for people with breathlessness.

Hilary was a non-binary nurse, preferring they/them pronouns. They started their career in theatres but soon moved into community respiratory nursing which they enjoy. At the time of data collection, their team was in a rural setting and entirely nurse led, doing hospital in reach as well as having a caseload of community patients and The Home Oxygen Assessment Service. Hilary answered my questions honestly and with thoughtfulness. They

demonstrated empathy with patients, an appreciation and understanding of the autonomy of the role and the challenge of supporting people with breathlessness.

Irene was the most senior nurse I interviewed. At the time of data collection, she ran a diagnostics service for respiratory patients to ascertain cause for breathlessness and has done a lot of work with the CCG at a nonclinical level. However, she appeared grounded by her clinical practice as a CRNS referring to loneliness, isolation, and the challenge of living with breathlessness every day. She talked about the job satisfaction of home visits, taking the time to unpick “a ball of string” of all the complexities of people's lives. Irene looked at the problems and solutions from a strategic, policy driven approach, aware of the challenges of providing services for a large population and the growing demand and the challenges for doctors; different from other participants who described a more individual personal approach to care. She voiced her own challenges in not being able to give solutions to community nurses who struggle to support their patients with breathlessness and look to her for guidance, she described feeling inadequate which highlights just how challenging supporting people with chronic refractory breathlessness can be. She referred to having COVID herself and the opportunity for empathy in really feeling the limitations of being breathless.

At the time of data collection, Janet had been qualified for 26 years, starting her career on a Respiratory Ward. Following this she moved to Practise Nursing where again her focus was respiratory care, gaining a diploma in Respiratory Practice. Following this role she joined the community team she was at the time of interview. Janet gave a very honest interview reflecting her struggles at the time both personally and professionally in the global pandemic. She referred several times to the isolation of the community respiratory nurse role, in making acute decisions and feeling very alone in doing it. She identified her frustration in not feeling she had medical or managerial support in place when asking for it in acute situations. The mood of the interview really struck me because whereas others talked about their passions

and positive aspects of the job, Janet was quite matter of fact about her enjoyment but more focused on the current challenges. Unlike the other participants, Janet did not end on a positive note or talk about the opportunities for nursing people with breathlessness in an optimistic way. Janet was authentic and honest, reflecting the times these interviews were undertaken with restrictions in both society and the NHS.

Katy had actually been ready to retire when the Covid pandemic started but returned to clinical practice due to a shortage of nurses. She has spent most of her career in respiratory nursing, with the last 15 as a Practice Nurse and Nurse educator for spirometry. At the time of data collection, she worked in Pulmonary Rehabilitation, supporting people on the program. She was incredibly positive about her role expressing genuine affection for her patients, her dasein reflects the temporality of her career, her personal and professional fulfilment in her current role. She talked about how improving her knowledge base can bring confidence to a patient consultation and compared 2 patient scenarios when she had less confidence at the beginning of her career and one with more confidence as her career progressed. The environment of pulmonary rehab is quite different to the varied requirements of caring for people in their own home. Patients that are able to do pulmonary rehab are generally motivated, capable people who often do not have advanced disease. Therefore, while they might be breathless, caring for this cohort of people is quite different to the caseload of a lot of CRNSs. Katy demonstrated that the positive measurable outcomes and rewards of helping people improve their quality of life can be very beneficial to the nurse personally and feel very rewarding.

Linda, the final participant to be interviewed, was a long-standing friend of Katy's. She too was on the cusp of retirement having been nursing for 38 years, most of it in respiratory nursing. She was a practice nurse in the past but at the time of data collection, her job was

as CRNS. She spoke of her long-term interest in respiratory and awareness of lack of services for respiratory patients for many years, which inspired her to take her current job focusing entirely on respiratory patients. Linda's years of experience have given her confidence and competence in her clinical practice reflected in her patient story. Her account focused on her role recounting what she did rather than how she felt about the situation. Linda was very positive about her role and the importance of caring for patients with a long and unpredictable disease trajectory.

Appendix 9: Examples of crafted stories

Andrea Interview 1

Crafted story

'Breathlessness is our patient group's most disabling symptom. My role enables them to have mastery through giving advice on bronchodilators, giving support around pain, mental health and anxiety because breathlessness is a multidimensional, complex phenomena. What drives me is I can put myself in the patient's position: I can see the terror in their eyes and imagine how that feels. What is more frightening than thinking you are going to die gasping for breath? Many of our patients live with this daily and are terrified. Nobody should suffer like that.

I have a patient who I have been caring for her for 2 years. She has the most severe breathlessness I have witnessed. I don't know how she manages, caring for her breaks my heart. I have worked hard to make sure she has everything, but I can't do anything else. I have felt really upset at times knowing that she gasps for breath just to have a wee. Nobody should suffer like that, it really hurts me to see her suffer like she does. I ask why can't I do more to take the suffering away? I feel caring for her is humbling and sometimes I feel I am failing her. I visit her monthly and I know she values me because when she was looking for a bungalow she looked for a property within my area so she could stay in my caseload,(tearful) I feel this validates the hard work I put in and I recognise that if I am getting it right with this lady I can model those behaviours with other patients. But I don't know how she manages it, she is one of life's positive people, she is inspiring to me.

Respiratory patients are generally very grateful which makes me feel valued. No two patients are the same which makes the job interesting, yet it can be draining and demanding, especially when supporting their psychological needs. It consumes me emotionally to care for this group of patients, I recognise there is an emotional cost to me. In our team clinical supervision often doesn't happen and if it does it doesn't always feel particularly beneficial but we are good at supporting each other and the trust offers a range of support, aware of the need to support staff with their health and wellbeing.

While I recognise the value of physios, dieticians, psychologists and GP's, I see nurses as the lynchpin in the provision of care. There are many barriers in place, but we don't give up advocating for our patients, we are not constrained by role in the same way other clinicians

are. Reflecting on my role as a community respiratory nurse I can see it offers challenges similar to oncology and palliative care which I have never really acknowledged before. Yet I have always avoided these jobs because I didn't feel I could cope with the day-to-day tragedy and wanted to preserve my own self-care.

My role is a specialist enabler, coordinator and facilitator. It is to wrap care around the patient. It is not task orientated or tick box but aims to improve the experience of the patient. I feel that if I don't do it, it doesn't get done because there are many barriers in place. If the patient is not at the centre, we don't give up, we don't stop [trying] for the patients. Other healthcare professionals might say that isn't their role, there is more definition to their role but as nurses we will advocate to the bigger arena. We do not stop at the gate: we open it and go through it, if we hit a brick wall, we will climb over it. Nurses are instinctive, we have a professional curiosity and do not let go until we are satisfied. If there is a need, nurses will keep going to find another way, we are resourceful'.

Commentary

Andrea comes to this patient encounter with a mission to address their whole lived experience of breathlessness, a challenge for any health care professional to achieve completely. She is assured of the need to engage with her patients, confident in her role but with high expectations of herself. These expectations are shaped by Andrea's thrownness, and the temporality of dasein. The mood sits heavy for Andrea and as she describes the encounter with the patient with severe breathlessness, she attunes to the present and future possibilities of her role and the costs to herself.

Andrea can put herself in her patient's position and can see the burden of living with breathlessness. She recognises that these ongoing experiences of breathlessness bring terror and fear of death, an existential fear that cannot be denied when breathlessness permeates every aspect of her patient's lives. For Andrea this fear has permeated her life("it consumes me"). Heidegger speaks of in being-toward-death if we are to live authentically.

This fear of death, explicitly demonstrated in severe breathlessness (as the ultimate experience before death) cannot be denied by patients and their families, or by Andrea.

Andrea recognises these symptoms are particularly severe, the worst she has witnessed.

She has seen many people with breathlessness in her career of 27 years and has an idea of what to expect for patients with respiratory illness. Her expectation of symptom burden is challenged by this lady's experience which leaves her unsettled, exposing her expectations of herself when caring for this lady. In witnessing this lady's symptoms Andrea has her own existential awareness of the depths of human suffering and indignity. She is distressed to see this suffering and to feel that she cannot do anything to relieve the suffering. Witnessing this suffering hurts her personally, beyond her nursing role because her close connection with this lady means she is also living it. Andrea's witness enables her to leap ahead in her solicitude. She feels she has an understanding of her patients' experience; and in acknowledging her own distress she shares in the distress of her patient. Andrea is clear that her nursing role requires her to have tenacity and determination when advocating for her patients and caring for this lady has made her question herself as with this lady she does not feel she is doing this because she is unable to take this suffering away. This adds to her distress at witnessing suffering, there is also a feeling that she is not doing enough.

Andrea knows that despite doubting herself, she is valued for the care she gives this lady.

As a result, she will continue to support her other patients as she supports this lady despite recognising the personal emotional cost. In engaging in this interview, Andrea has reflected on her role as a CRN in comparison to other nursing roles in palliative care and oncology, roles she has always considered to be particularly emotionally challenging. She has avoided these roles in order to preserve her own self-care yet concludes that the CRN role is comparative to these roles. This is not something that Andrea had considered before. As Andrea acknowledges the emotional cost this role has to her she recognises she has not been able to preserve her own self-care yet she is clear she will continue advocating for her patients. This reflects the complexity of the nursing role, that while there is an emotional cost

to Andrea of witnessing distress, she simultaneously feels valued and inspired by her patients and will continue to do what she is doing.

Interview Reflections

10th Dec 2020

I have just completed my first research interview. I am so disappointed because the Google meet and the MS teams did not work so I was unable to record the interview. This meant I had to write pages and pages and rather than really tune in to what the participant was saying I was very mindful of trying to write everything down to really capture not only what she said but how she said it. At times she had real emotion in her voice and at one point was tearful. When this happened, I too felt very emotional, I guess because to hear someone else feel the depth of emotions I feel with breathless patients was somehow very consoling. However, I think I inadvertently moved her away from this discomfort and distress and on reflection did not dwell in that emotion she was feeling. In the future I think I would try to be braver and more confident to explore those feelings in a greater depth. She was incredibly insightful, thoughtful and considered in her answers and I am very regretful that I could not record that to reflect on it for the future. What was really encouraging was her agreement about vulnerability and breathlessness and the challenges of witnessing this and being unable to influence it. She spoke about a lady who was relatively young who she had supported for two years, this convergence of relationship extreme symptom burden and chronic illness left her feeling very challenged and questioning if she could have done or could do more. She described what being a nurse meant in terms of advocacy for patients and was incredibly empathetic regarding her patients' personal encounters with fear and breathlessness. She was a really wonderful participant and I feel very mindful that I want to do what she says justice and use her data to the best of my ability.

Further reflection 30 Nov 2021

Looking at this same interview I am interested that my initial reflection was to positively affirm my own experiences without focusing on the participants' use of language and reflection on what being a nurse means to her. This proves the challenge for me, as a nurse myself to predominate as a researcher. My roles as nurse, peer, student can be blurred by what is being said, I need to keep focused on what I am aiming to achieve from these

interviews and the analysis that will ensue. That said, i guess i also need to acknowledge my own interpretation based on my knowledge/experience/shared role

Reflections after crafting the story 13th Nov 2021

This story, and my encounter with Andrea says to me that she is a passionate nurse. Not only is she highly skilled with practical knowledge and ability, she is empathetic which enables her to relate to her patient with humanity and deep caring. She embodies her role as a nurse, demonstrated not only by what she does but how she feels. She recognises the power and responsibility she holds in advocating for her patients and is personally invested. She feels their pain which is deeply uncomfortable as she has a personal desire in her to make things better and is distressed when she cannot do this. She is at the point with this lady that no amount of doing (equipment/practical things) will help take the indignity of breathlessness away, it is in being-with witnessing the distress and continuing to visit (she could refer on to palliative care and discharge her from her caseload) that demonstrates her humanity but causes her pain. This story resonates with me and I can relate to this feeling that somehow just showing up is not enough, it will never be enough. Our heads tell us that is how it must be but our hearts tell us it is not enough. We see our roles as nurses “to fix” and feel impotent and exposed when this is no longer a possibility. All we are left with is witnessing the patient’s distress which challenges us to step out of the boundaries of clinical practice and into a human-to-human experience, to dare to consider what it feels like to experience such discomfort, fear and disability. The mood of this interview was heartfelt and sincere. Andrea was very engaged with the subject area: able to share the emotions evoked by caring for this patient and the wider patient group.

I was somewhat distracted in this interview due to IT issues (I was unable to record the interview so had to write the interview verbatim, or as close as possible) yet felt very moved by Andrea: her honesty, her generosity in recalling a situation which caused her to be moved to tears and her clear humanity as a nurse.

Carrie Interview 3

Crafted Story

'I think breathlessness is multilayered. There's always an element of wanting to fix it, and also a concern, almost still, maybe apprehension that there might be something acute going on. I mean, that's sort of like one layer. And I think there's always concern for the patient's safety. So I still feel like that, there's a level of concern, anxiety that there's something that needs dealing with immediately.

I think when you move on from that and you know the patient, or you've come to the conclusion that it's not acute then it's a different level. I think there's probably a feeling that, being hopeful, that you can help. You want to help their suffering because they are suffering with these awful symptoms. I think there's always that sense of unease, while you're waiting for things to settle and hoping that they'll settle. And I think if it's more of an ongoing, Intractable breathlessness there's just a feeling that I hope I can help this person. But through experience, knowing that sometimes I can't help as much as I'd like to. And If you can't do that, there's trying to find ways of supporting them through it, that's also a level of determination to try and see that through.

I think there's a few [patients] that stick out, there were two that were probably that were difficult, well it's always difficult, but perhaps not as good an outcome as I'd have hoped, and one was more positive.

[This was when I first started as a Respiratory Nurse.] I had met [this lady] about a year before, and she was struggling then and I think we called to review oxygen needs because she was in a nursing home and she was dying. I felt quite shocked [when I walked in the room], a bit of disbelief really because she was still alert although drowsy. She was so distressed and uncomfortable, really fighting for every breath in a room on her own in the nursing home. It was just the sheer breathlessness: her mouth open gasping for air, it was quite diabolical (laughs), I'd never seen anything like that; a respiratory rate like that working that hard to breathe. I [thought] Oh my goodness, how could this happen? I don't know how long she'd been like that, possibly a couple of days because she was in the dying stage. No one [the nursing home staff] had given anticipatory medicines despite them being written up on her drug chart, probably, just through lack of experience, I think they just thought this is how it was [with ILD]. If someone is in pain or dying in pain, you would think about a syringe driver. But it was just the fact that because it was this [ILD], nobody had [considered it]. I was

with a colleague who just started with the team and I remember us both just looking at each other and maybe not saying it but we were both quite shocked but of course you have to be professional and I was ringing GP and things like that, you just cover your feelings up. But that feeling obviously didn't go away. I felt quite horrified really and upset.

I remember calling the son as well [to tell him] she hasn't got that long to live. And I remember him describing it as "this damn hideous disease". I was glad that I went in, that it was me that they had [called] to review her oxygen needs at that point. It was a relief to think that now we can do something that can help 'cause she was dying and that's what she needed. I think eventually things were sorted out, the GP came, and they did start the syringe driver. And in the end she did die peacefully, she died a couple of days after that. It was just the surprise of it, it was awful and it stayed with me from the beginning. I've not seen anything like that since, thank goodness. There was this thought that there must be something better than this and there is. That was 11 years ago now.

There was another lady with end stage interstitial lung disease, she had fibrosis. She seemed reluctant to try different things and nothing seemed to help [her]. She had intense breathless management from a specialist we have in the team but she said that nothing helped. She had had past experiences of having bad reactions to medication, so she didn't like trying different things, so she just struggled. I read back [through her notes] and I thought; there was almost a feeling that I didn't do very well there, we never actually helped as much as you would have hoped, and I think there was a little bit of a feeling of failure. I feel like perhaps I could have done better by visiting more and being there but it was in March [2020] when Covid started and we couldn't do that. Other people [in the team] had to visit my patients [because I was shielding] so I couldn't actually do any visits, [it made me feel] a little bit of a failure, there was almost a feeling it was unfinished. I don't know if that would have helped a situation or whether she'd have even wanted more support, but it was the fact that I didn't really get the opportunity to do it. Pre-covid I would have gone once a week or more I think that would have helped, I'm not quite sure if she would have accepted that anyway, but it was kind of left so did feel a little bit unfinished.

Then there was a really different experience probably about 4-5 years ago, a lady who I got to know really well and knew her for years. She was an ex-nurse and she also had interstitial lung disease. Her end stage was slower, it was 18 months or so. I think this gave her time to talk about her fears and feel that she was very much supported by myself and then eventually palliative care nurses. She was accepting of the fact that she was going to die. And she died very, very peacefully and in a very accepting way. She died well, it was a very good death. When I spoke to her I asked how does she process all this and she said, I

don't know. I asked her if she could feel the breathlessness. And She said no, I can't feel it and that was amazing. So it was very different really. I think part of it was the woman herself and the fact that she was budhist; had Buddhist friends and that was her mind set. It was almost easy for her to take things on like Breathless management and accept that breathing techniques and relaxation might help. We really planned it and worked together. It was very sad but I didn't feel a failure. I often think about her in a positive way, not a negative way, so it's very varied.

We are not made of stone and often we know these patients sometimes for years and are very involved so when they are struggling with symptoms it can be like watching a loved one. I do think about it outside work and there's a sadness and a grief, especially when they die. As Health care professionals there is an element we shouldn't get emotionally involved but in the community you have a long term relationship with that person so it is a different relationship from being a nurse on a ward, and even a palliative care nurse because we have been involved pre-end stage. I had a close relationship with the ex-nurse and went to her funeral which was lovely but I did feel sad afterwards. I think professionally that I never want those things to happen again so it gives me determination to see things through. There have been periods over the years when it can be traumatic, perhaps not the same way as if you saw a road accident, or perhaps if you worked in A&E and that sort of trauma, but I think sometimes the whole experience can leave you feeling upset and quite emotional about it. If I could find a colleague I would take the opportunity to debrief but as I might get upset or cry, I would want to know it wasn't going to go any further. I shared my feelings with a colleague once and was greeted with a shrug of the shoulders, no offer of engaging with conversation. We do have group clinical supervision but often I do not want to share how strongly I feel, it's too intense and I am not sure how it will be perceived. Maybe a 1:1 is the place, but it depends on the person. I wouldn't speak to a family member. I think generally I would just think about it, often in my car after a visit, reflecting and processing my thoughts before driving to the next person. Eventually your feelings wear off. Sometimes there's a little bit of a feeling of failure left over, like with that lady but other times a sense of achievement and relief. It's complex actually.

Even though I'm a respiratory nurse I still feel as though I'm undertrained [in breathless management] to a degree. I would love to have expertise as so often it is joined up with other things but breathlessness is the main theme. There don't seem to be any sort of short courses on breathlessness but maybe my expectations are too much because I find with breathlessness, there's always that feeling that either I'm hopeful that I can help, but then

that thought that I might not be able to, I think that that is probably because of my past experience and it's accepting that I might not be able to and what do you do then I think.

Being a nurse can mean being there [for patients] for the long haul, we have a different way of looking at things than function and adaptation. A lot of it is being with that patient with their struggles. It doesn't have to be holding their hand but actually supporting someone through their distress and spending time with them, focusing on that person and their emotions and feelings. We do think about their spirituality and how they feel about their life and their future. Nurses can be like a dog with a bone, determined to help and offer support'.

Commentary on Carrie's crafted story

Carrie cares deeply for her patients expressed by how she thinks, feels, acts and works. In this way the thoughts she shares regarding her experience of supporting patients with breathlessness go beyond her clinical role as a CRNS in sharing her own feelings. This attunement, how she finds herself is demonstrated as she describes the personal impact of care, the costs of it but also the rewards of feeling connection with her patients. Carrie's thrownness as a CRNS is conflicted between how she carries out the role and how she perceives others consider how nurses should be when she mourns her patients. Carrie does not differentiate her professional position of care from her personal feelings for her patients yet is conscious that some might consider she should not have this emotional connection in her work.

The experience of care for Carrie of being in the world is temporal and existential; clinical experiences continue to shape, challenge and inform her personally and professionally over the span of her career despite her years of experience. She seeks authenticity when faced with the personal challenges of loss and grief, faced with being-toward-death through her patients own suffering and death.

Carrie's empathy for her patients demonstrates a particular mode Heidegger identifies as solicitude through leaping ahead for others, to leap forth and liberate pertaining to authentic care (Heidegger 1962 p158). Yet Carrie also acknowledges her desire to leap-in, to "fix":

whether that is practically or emotionally, recognising the variability and complexity of supporting people with breathlessness.

The encounter with the patient in the Nursing Home confronted Carrie and her colleague with shock and disbelief that such suffering could be a reality for another human being. For both of them at the beginning of their CRNS careers it was a drive for Carrie to question “there must be something better than this and there is”. This question is both existential and practical and Carrie describes the determination she has to help and “see the care through”, care that she is involved in. This became apparent when due to the COVID pandemic Carrie was unable to continue visiting her patient at end of life which left her feeling this care encounter was somehow “unfinished”. This highlights Carrie’s personal stake in the care she provides and her existential need for this.

Her fallenness into the role of CRNS sometimes results in her feeling she is unable to share the emotional costs to her from her experiences in Clinical Supervision and she must internalise these feelings. Is this because she feels these emotional costs are as a result of her own choice to get involved or because the resources provided are inadequate in supporting her needs? This traditional conception of the nursing role “not getting involved”, could be blurred somewhat in community nursing where relationships between nurses and patients can span many months or years. This concept of nurses getting involved seeks to question what society expects of nurses over and above our own limitations. The idea that nurses have an inherent power to care and give altruistically and infinitely, has been exposed during the COVID pandemic.

Interview reflections

2nd Feb 2021

I enjoyed this interview today because not only was it somebody from my team that I know well but I felt she was open and honest and managed to blend her own experiences and the patient's experiences. I am aware that sometimes my role as a nurse, researcher and peer can be clouded and I lose the clarity of my role identity as researcher when steering the interview.

I feel some of the themes coming out are around personal expectations within the role as respiratory nurse to improve the situation, primarily looking at practical resources rather than considering the personal resources of the patient. It was clear to me from some of the scenarios that some people have more emotional intelligence than others, helping them accept and move with their experience while others are unwilling to engage. The question that seems to challenge a lot of people is considering the role of the nurse in breathless management, apart from involving the rest of the multidisciplinary team. A lot of answers reflect on the holism of nursing and the time to consider the wider perspective, as opposed to colleagues that are focused specifically on one aspect of care. This participant also talked about joy in nursing and the satisfaction of being part of a patient encounter that is positive and the sense of personal gain when things work out well, even if that is a good death.

Reflexive thoughts after crafting the story 30th Nov 2021

Carrie was the only participant of the 12 interviewed that I knew prior to interview. This prior and existing knowledge has informed how I read the transcription coming from a place of knowing her before and after the interview. This familiarity and comfort with each other might explain her incredible openness and honesty when answering my questions, probably more so than any of the other participants. She knows what my research is about so came into being a participant knowing I wanted to focus on experiences from a personal perspective, she gave me this which has provided me with a lot of rich data. I was aware of this element of trusting the researcher when answering questions that disclose vulnerabilities in the research process and tried to mitigate through asking open questions that set the scene and put the participant at ease. However, this was always going to be challenging on a video platform between 2 strangers who have met for the first time. This subject area asking nurses to share their experiences was always going to be challenging. Carrie's reflections on the limitations of Clinical Supervision and the question of getting involved resonates with me in personally in questioning my own emotions when witnessing distress, somehow feeling complicit. This aspect of the study needs further exploration.

Esther Interview 5

Crafted story

'I've been trained forty years, did intensive care for 20 years, and critical care outreach for 10 years. I was getting a bit old and a bit tired and couldn't do 12 hour shifts so 10 years ago I moved into the community to be a Respiratory Nurse. I retired for 2 years but then came back into community respiratory nursing 2 days a week.

Moving into the Community is that strange thing where consent and the privilege of being in somebody's home mean relationships are very different to being in critical care. [In critical care] there are a lot of assumptions about best treatment and that sort of thing so it was quite difficult and it took me at least two or three years to settle into the job. I found a lot of the time I felt "i'm not doing anything". The work, the pace of the work and how you measure it is very different.

I think I do look very much at breathlessness as their perceived experience and their subjective approach, but I also really look at work of breathing which I think comes from my background, you know how hard they work, my assessment skills are very much towards that, and they can say "I'm really breathless " and i say well you've you've not drawing breath, while you've told me.

[Breathlessness] is distressing for patients and when I'm talking to patients, I say it's your experience, so you tell me how you feel. And sometimes I liken it to when somebody is talking to me about pain. If they've got pain, then that's it and if you're breathless doesn't matter what I see, you're breathless and I think that's quite a good way of dealing with it sometimes because you can say well you're not working very hard and you just managed to do that, but if they still have that sense then they're breathless because it's such a subjective sensation.

I loved doing the pulmonary rehabilitation and I loved working with the physios because of the pre assessment and the post and how far you go, I learned a lot doing pulmonary rehab.

But then you've got the other end where you know that they're moving towards the palliative approach, I think that becomes a little bit more different and I'm quite happy to recommend medication for that. When it's getting to that point and you just see the panic and fear in their eyes. I do think medication is not brilliant, not well evidence-based in some ways, but

actually it's worth persevering because there's little else at end of life when they're really short of breath. That's the thing I hate the most. You have less in your tools to help them.

There is one patient I can talk about, he's on oxygen therapy, so I went to see him at home because he was only on ambulatory oxygen and I haven't met him before. It was in the summer and he's a big man and a strong man, you know, but old, in his 80s, but looked younger, so much younger, until I checked I couldn't believe it. He was so frustrated. But he frustrated me as well, because he wasn't listening. He met the criteria for LTOT but wouldn't have it. He's more towards the end of his Life, but not quite palliative and he and his wife were resistant to change, he's still in that phase of resistance. And it frustrated me and made me angry one day, because I thought well I'm telling you things and you're not listening. And I think there was a bit of frustration about the COVID situation, he's an example of that. If he could be doing other things that are distractions, his focus wouldn't be sitting there thinking "i'm feeling breathless", we can't offer those distractions, patients make their own distractions don't they?

He has an unwillingness to accept that his condition has moved on a little bit. I did something I told him I was going to do: All our patients have standby or rescue medications and I stopped his [because he was over using them]. I suppose my main thing from him is I could see where he was [in his disease trajectory] and what he wanted I couldn't give him. We were moving towards an acceptance that actually this is his new normal which I didn't say, sometimes there are some patients you can say, do you think this is perhaps where we are now, that we're not going to get back to where we were? I couldn't really have that conversation with him because he didn't know where he was in that.

By the end of each visit we start to get there, and then the next time I'd go he was back to that angry frustrated thing and because you were a Community nurse and you're not seeing them on a daily basis you haven't got a program to move them forwards. And you don't know what's happening in between those two visits. But I think there is a lot of frustration with him and I might have probably wanted to push him a bit more towards that acceptance of the new and he's not ready. So I've had to step back and go right, this is where we are, I'm managing you in this way because it's safest for you, with steroids, and then we know use your oxygen. I let him use his oxygen however he likes. And we walk and we talk when we go. But it's it doesn't feel very satisfactory for me because I don't think he's happy.

You have to work with the personality that you have. And in some ways, that's probably what's keeping him going. He's my one that I find frustrating.

There are others on our caseload where we aren't winning, it's not just me. I found them a bit circular, not moving forward and I was thinking so why am I seeing them? Because we do have to be very careful about how many patients we see and why we are seeing them and I always say, so what am I doing for this person, not a lot. I'm not making him feel better and not helping with his breathlessness because we've gone through all the things that I can offer anyway. I've learned that you can't do anything with a patient at home if they don't want to.

But he is frustrating and when I first went I wanted to sort them out. And I couldn't. I think it was that thing: right if we just do this, and he didn't. There was a phase where I really did want to chuck long term [oxygen therapy] all of that at him, I'm still sometimes a secondary care nurse of "Do, treat, do do". But actually I learnt and he's taught me a lot about oxygen that that's not always the best thing, and if patients don't get on with it it's more trouble than it's worth. It's evidence is only to prolong life. It's not a treatment for the shortness of breath.

So I just backed off but I do feel more confident that, when he rings me, I know how I can support him and his wife. I think it's about supporting the pair of them and how they support each other.

So I would say, I felt frustrated and I think there are quite a few patients that we feel frustrated with. I feel that I'm not helping them, they're not going to change how they get breathless or how they manage their breathlessness without us restricting them like I had to with the steroids.

I think about the difference now from when I first started. I can remember the first time I had experiences like this, I felt completely lost and unsupported. I used to really feel I haven't done anything; I haven't helped him that's how I felt and I also felt a bit cheated because I was going to do ambulatory oxygen assessment which should have been just a quick walk around the garden and it wasn't.

When you work in a secondary care environment, you can go hah! you can go in and say what's going on? [In the community] I don't know what to do, i'm not sure if i've done the right thing and I always find when I walk away from patients' home, and I feel unsettled, I felt I was leaving something undone and I found that very hard, but I think over the last few years i've learned that actually i'm not the saviour. I did feel challenged professionally [with this gentleman] so I went back to my colleague, who knew the patient much more before me, she said oh he's a nightmare, a nightmare, I call my grandson a nightmare so it's that sort of thing because they are challenging but also funny and interesting people, you know so that gave me some confidence, and I said, this is what i'm thinking and she said we won't get

anywhere with that, but you might get there with that, and you know I tried that and thought well at least having somebody to talk to which I do have in this team who is more experienced in the Community setting said the same thing.

So professionally that's how I like to work in the Community, some of our team have the same patients and they see the same patients. And I think that's not healthy for them or the patient, I think it can be really lovely in terms of the relationship that you have if you do become friends with your patients, you know you do sit and talk about the tellie and the knitting and things like that which is lovely, but it's maintaining that professional role that you're doing , but you can move away from the professional role and what you're trying to achieve. I think I would feel limited in terms of how I would be learning and expanding and I also and I think I would not be stimulated enough if I just had same patients, I need a range and I, like the new patient, I do like the new stuff, and we've had to take on other stuff. But that's just my experience.

When I first started in the Community, I didn't get it and understand how the culture in primary care worked because there didn't seem to be that collaborative team thing: I couldn't see it, as I would see it in secondary care. I still struggle with it. I went and did 2 months on ITU in April and May this year [due to COVID] I haven't done it for 20 years and i went in and on my last day, on the way out, i said to my husband "they get me", you know they are all completely different people, some from an old time, but that really strong ITU team approach is different, I don't regret leaving at all, i love what i do but most of my career was that and its adjusting professionally, how i get that support is harder i think in a community setting.

[This patient story] reinforces what I find challenging all the time, that consent and the privilege of working with patients in their home environment. I think it's that thing that I find surprising and interesting every single time I go into someone's home and see how they live and how they have to tell you their story. I think it reinforced to stop going in and trying to over treat these people or tell them what's wrong with them when they know what's wrong with them in their way, but also just make sure that you keep them safe in terms of over taking steroids or something, so for me it was such a shock. I do see it as a privilege going into people's homes, and I do like it, but i'm still learning that you're on their territory and the things that make up that holistic treatment plans self-management doesn't stop there; it's the thing with the wife, it's where they live, it's their property, it's how they are: you see a lot that you would never see in secondary care and you have to honour that you have to say that's your choices and accept those choices and help them come to terms with their own frustrations and limitations. In that particular way, so I have learnt that, again.

Every time I have this thing, i'm gonna go in and do this, do that, do that and actually no, i'm going to go in and listen and see where we're going to go where we/ he/ they want to go really, and see what my role is, I am finding my role.

And I think that's quite important, because you can overdo it can't you. So I definitely went through that process of overdoing it and then backing off with this chap.

just learning that the balance of power in the therapeutic relationship is theirs, they have the power. It's the therapeutic relationship that you have to manage, I think, with them.

And I think it's partly because they're not easy wins. With heart disease, there have been some amazing moves and it has transformed how we manage heart disease.

But COPD and lung conditions like pulmonary fibrosis, it's just awful.

You know when you're talking to somebody with pulmonary fibrosis, and they go

I never smoked. I'm healthy and I'm stuck here, and they are angry, and their consultants can't give them the answers why and that's really difficult to deal with sometimes. I find those patients take that anger out on us because we're there, we are able to bounce off of it, but it's frustrating as to why there hasn't been more Jazzy research. One breakthrough would make a huge difference to how you could market the condition or how you could take things forward.

I think that the [community respiratory nurse specialist] role that has evolved has been hard won and should continue to evolve. Nurses do prescribing and have clinical assessment skills that we have from our [previous]experience. I think the most powerful thing is taking a holistic approach with their listening and looking at the patient as a whole person. If you come from a district nursing background, it's phenomenal I would never [have that knowledge]. I can't underestimate some of my colleagues, and what they know and how they just sort some things out so well because of their background that nobody else could do, you just think oh wow that's really good and i'm glad I know you because that's really helpful, but I know they come to me, for other things that are possibly a little bit more clinically

challenging and I feel more confident about other things like changing prescriptions and reducing prescriptions. I do think it's been a hard fought role to achieve within the profession, and I think it's something that needs to be held on to and celebrated really, not everybody can do this job. I think that people look in and say, you're a nurse, but your experiences that have got you to that point have taken a long time. And the fact that you can keep patients

out of hospital, and they feel supported and able to self-manage I mean, I think the self-management thing that we do is really important for our patients. My patients don't sit there and just wait to be treated as much now. I like how that has evolved and I think that will evolve even more because I think that's how nurses lead patients self-managing with the right sort of support and knowing where to go for help.

I think that's the nurse's role, that's different [from other AHP's]. And I think nurses are taking things forward much more, trying to do things differently; let's set up this and see how it goes. Let's work with the voluntary sector. something comes up and we give it a go. Don't We? Well that's how I see it. More than other professions. I don't think nurses are as protective of how their role is perceived if they feel confident in what they are achieving in their role. Other professions are a little bit protective of their role. But as a nurse I'm leading on this and I'm going to take this forward. And you know, most people will support that. So I think that's where nurses do have that good idea approach'.

Commentary on Esthers' crafted story

Esther frames her story within her long career, predominantly as a critical care nurse. She recognises that over 30 years in critical care of personal and professional experiences informs her professional identity and current practice in community nursing. For Esther Dasein, that is, being in the world is informed by the totality of her experience including her position today. Her lifeworld is intrinsically shaped by temporality engaging the past, present and future of dasein. Dasein connects us to the world just as we impact the world. This is evident for Esther as she navigates her situatedness in community nursing from the personal experiences and prejudgements of a critical care nurse which has shaped her professional identity. For Esther, coming to community respiratory nursing that she identifies as quite different to critical care, she feels a dissonance that reflects in her attunement.

Esther identifies her desire to “do, treat, do”. This approach to care is leaping-in and known and familiar to her. Measurable outcomes give her the satisfaction that she is doing her job. Caring for breathless patients in the community is not easy to measure, quick or treatable

which challenges Esther personally and professionally. This discomfort is demonstrated by Esther's view of palliative care. In witnessing "panic and fear in their eyes" Esther cannot avoid the reality of authenticity and being-toward-death. In the absence of being able to "do, treat, do" Esther feels exposed and vulnerable, stating "that's the thing I hate the most". In a career of intervention and measurement, Esther has avoided the discomfort she cannot escape in community respiratory nursing, facing palliative care. This authenticity of being toward death is too much for Esther, she would rather function inauthentically as she feels confident and comfortable. This is also demonstrated when Esther identifies that her breathless patient has advancing disease which is most probably resulting in his worsening symptoms; yet she is reluctant to address this disease progression with him because he is angry and frustrated. She matches his frustration with her own missing the opportunity to address his thoughts and wishes regarding his future care.

While Esther is now in the world of community respiratory nursing, and this world influences her, the temporality of Dasein informs her decision making. Esther's personal discomfort with palliative care has led to assumptions that medication is the only route to managing symptoms, oxygen should be part of treatment and a program of rehabilitation should be adhered to. This desire to frame care primarily within practical intervention is another way to detach from personal suffering and connection. Heidegger's terms *techne* and *machination* are understood in terms of technology fulfilling purposes that "are alright but do not get to the bottom of things" (Inwood 1999 p211). Focus on such intervention can enable disconnection in relationships. As Esther struggles to consider outcomes that are not measurable as therapeutic care, it is unsurprising that her desire to "care" is framed in machination and in leaping-in. Although she mentions therapeutic relationships, Esther does not recognise the positive influence of emotional support and affirmation that her relationship with her patient and his wife will inevitably have given them because this is a difficult outcome to measure.

Interview Reflections

17th Feb 2021

This interview was with a nurse with 40+ years' experience, as she described, at the end of her career having come to community respiratory nursing from critical care. Her take on the role was very functional and her descriptors were around frustration with patients that would not listen or do what she felt was required.

I think that anger and frustration can be emotions that do not always sit comfortably with us but are an expression of our thoughts and feelings going into a situation and she was open and honest to share what she was feeling. It made me realise that many people come to the role of nursing with different backgrounds, life experiences, expectations that feeds into their role as a community respiratory nurse. It is probably a good thing that we are all different and are able to approach the job differently, but I was interested that she did not consider the emotional/psychological component of breathlessness and always drew on the functional benefits of her intervention. At one point she said that she did not feel it was helpful to get too close to her patients and was clear that she should remain within her professional role. This made me challenge my own approach to clinical care and consider, what I see as therapeutic use of self, and ask if this is in fact getting too close and moving away from a professional relationship. However, I believe that in engaging and empathising, patients are able to identify and connect with their own vulnerability which plays a big part in their thoughts and feelings around their health and wellness especially regarding their breathlessness.

It seems that themes around role expectation or expectation of role have come out of the last couple of interviews with the nurses considering what they can do and should do and being able to do this (The patient engaging and letting them offer that support, open up to another way of approaching that situation) influencing the nurse's sense of satisfaction and self as a result of that clinical encounter

After crafting the story 4th Jan 2022

This nurse spoke at length about her thoughts and experiences, the interview transcript was 17 sides long! Her account, differing from others, focused less on her empathy and distress

at witnessing breathlessness but identified feelings of exasperation in clinical practice.

She was open and honestly shared how she feels angry and frustrated when a patient does not take her advice regarding breathless management, despite sharing his struggles as she sees it. She identified it was her acute clinical background that drove her desire in community nursing to intervene, fix and change. When this fixing was not possible, she struggled personally and professionally yet demonstrated empathy and self-awareness, keen to keep learning and developing her practice.

Her desire to avoid connecting with her patients and being vulnerable, being-toward-death in the light of their suffering is different to other participants for whom this seems to be a recognised aspect of the role.

Fiona Interview 6

Crafted story

'My first experience of community working [was in my previous job], I've always been hospital based before that so now I'm finding my way with the community and how all that fits together. At the moment it's tricky building relationships when you can't really sit face to face, meeting up, and all those sorts of things. I think everyone is just so overwhelmed, aren't they? You know, particularly community nursing teams and our team certainly really are struggling with the pressure on community services from secondary care.

[Breathlessness] is just such an intense symptom, isn't it? And it's often a very sort of stressed, intense environment between the person and carers and family, and I think that can make it quite emotive. I know a lot of people really struggle with the concept of breathlessness because they can feel it's quite a helpless symptom that people perhaps don't work in Respiratory will say, well, they're going to be breathless, we're not going to resolve it, but actually, I feel there's a lot we can do to support people and help people manage. Every time I see somebody you learn from every experience. I think the more you can equip yourself every time you go in with somebody that is breathless you are thinking and learning. You are reflecting; how could I have done that differently? Or what tools might I have been able to provide with that person? Or is there something I feel that I need to extend my knowledge or practice so I can help the next person? It's always a learning process as people are so unique, there are a lot of similarities with managing breathlessness, so every situation is just a little bit different, isn't it?

But equally, it is distressing, it's upsetting because you've had that interaction but when you leave it can sit quite heavily with you because you know that perhaps that person isn't going to see somebody else maybe not even until the next time you visit particularly in the current situation, so I think those sorts of things sit quite heavily when seeing people with breathlessness.

The other day in the office I overheard a physio, they'd been helping somebody with breathlessness, and they didn't know what to do. They just sort of listened to them but didn't necessarily know what to do. Personally, they were listening, but they weren't necessarily offering anything to help them change. That's the thing you just don't want to feel, you want to make sure that you don't feel helpless helping people. But I think that the more you feel you know, the more you feel you could offer skills and tools to empower people. I think that actually really helps you as well, rather than going in and just sharing a feeling of helplessness with people you know, which I think sometimes it feels like that perhaps. I get referrals, and it is somebody that maybe had a complex history in the past, maybe from their mental health point or anything like that, it just feels sometimes if people were able to explore and were a little bit more, equipped with tools to be able to map that situation that they would be helpful rather than needing to refer onto another professional. I suppose I do have quite a lot of skills with dealing with breathlessness in the moment and people with high levels of anxiety and, you know, it's always been something that interested me for years, but there's always more to learn.

I was thinking of this one particular woman actually who had pulmonary hypertension and was very hypoxic, type 2 respiratory failure, ventilation at home and her oxygen saturations were around 55-60% so yeah, really very hypoxic and very limited, she lived in quite a microenvironment. She didn't really have any family. And she was just such a lovely person, salt of the earth. There was a picture of her with the Queen on the wall and it used to make me smile. I think it's just really hard for those people that are so isolated which is so common with the people that I see. It was a struggle for her, but equally she was very stoic about it and she never really [complained], although towards the end of her life she became very frightened. Earlier on she was very philosophical. I think she was very strong but I think it is interesting, particularly with this lady, because we saw her regularly, she used to come into our Hospice team every week to the day centre, but there was a definite parallel between her level of fear as she approached end of life although clinically there wasn't much changing with her numbers or anything was different, you could tell, she knew in herself her path was approaching end of life. I always remember with her because I admitted her to the inpatient unit. She was there for a little while and I think she should have stayed but she was

discharged and then, sadly, she died a week later and she was found on the floor on her own which, sadly does happen quite a lot with respiratory patients that are very isolated, but it is very sad. [Caring for respiratory patients] there is a need for specialist skills, because people are so familiar at looking at cancer trajectories in palliative care that when they're not familiar, I don't mean to be disrespectful 'cause I know there are a lot of palliative care clinicians obviously really experienced with respiratory conditions as well, but I think when that's all you do and all you see, there's just those nuances that you know when you know people really well. I came into a call the next morning saying I'm sorry your patient died overnight. She was found on the floor on her own. When you know somebody really well, it sits really heavily but then you've got another three or four visits to go to that day, and you have to just go. You have to just go out to it. It does really affect you when somebody you know very well, you've worked with very closely for a number of, sometimes two years, seeing them on a very regular basis getting very involved in their whole world really so there's a lot of sadness when people die.

[There was} another chap I'm just thinking of who actually had IPF but he had a heart attack. I think it was in 1996. He came home from the hospital, and he hadn't basically left his armchair since and so his poor wife, who I had a really good relationship with. He was just a very tricky character, and he didn't really want me to come round particularly but he would let me in for his wife's sake and I think he had had more mobility in the past, but then with IPF, he just deteriorated and deteriorated. He had a high oxygen demand, but he also was very tricky with his oxygen use, and he'd often be piggybacking several different pieces of equipment at the same time, which was always a bone of contention with his wife because she knew he was only prescribed, whatever it was, but he'd be there trying to push 15 litres through all these different pieces of equipment. When people have a level of anxiety and social isolation, their anxiety can really project onto the people around them. And I think that's probably the same with you as a professional. But also, you know it does project onto you, particularly if I have a day when I see maybe four people that are full hour-long appointments, it's very intense. Feeling at the end of the day, it can be overwhelming. [Often people] are either very isolated on their own or perhaps living with another person, having one other family member that is solely responsible for their care. Which is why sometimes I think in palliative care there's not a lot of room for recovery. Because we're busy this has struck me much more in this role than others. So, I think sometimes there's not that space, you kind of just have to get on to the next thing, really.

I'm quite new in this new role, I've only been there three months though, so I haven't actually had any opportunity for formal clinical supervision. But that doesn't help at that moment,

there are always people to talk to but I think you end up holding a lot of that. It can be quite hard sometimes. I think not having that time to reflect there is, I suppose, a low-level grief in a way where you've got to know people very well, you know. It's very hard sometimes, saying goodbye to [that chap's] wife on the door and she's in tears and she's hugging me and hugging me and I know that she's going to shut the door and then just be shut in the house with somebody who's not that easy to live with or very tricky to live with. What is quite common for respiratory patients is they don't like to be left all alone at all. By the time I see them the disease has got so severe that they don't feel safe on their own, so they won't actually allow the person [to leave them]. And this particular woman used to go out for I think 1 one hour on a Thursday with her daughter and that was it. And this is way pre COVID and so there's a lot of sadness there for those carers as well. It feels it can sit quite heavily; you feel quite responsible for people. If they're isolated or even if they're not, because then you may be one of their only points of contact, personally and professionally. I certainly can't say that 5:00 o'clock or whatever time, I don't just shut off, it's very hard to shut off when you're working with people like this. I do think about people or dream about all of these things. I think personally it does affect your life and I think I might not necessarily be aware of it but I've become more aware of it over the years. But you know, if you have these intense experiences with people in the day, often you don't have anything left to offer at the end of the day, to your family or friends. I've got young children and you have to do it, but I think sometimes you haven't got a lot left to offer people, so I think it takes up a lot of energy and a lot of your sort of mental and spiritual energy as well. All those things that you invest and you give so much and people take quite a lot as well so you know you are giving so much of yourself that sometimes it comes to the end and you think I haven't got anymore. You know, that's it for today.

I haven't been working 'cause I left my last job and then COVID happened. So I haven't worked for a while. I didn't lose my job 'because I chose to leave but I'd lost that part of me and there was all this stuff that I was looking forward to doing with my children. And then it was COVID. I found that really hard. My youngest son started school this year, he's four and we'd been talking about this since he was born, I was going to have these six months to really enjoy life, you know I'll be there all the time for my older son picking him up and I'm going to do all these great things with my youngest and then it was just lock down so that was really hard at first, that first lockdown definitely, but thankfully, the boys are at school. I thought I'm just not sure that I can keep home-schooling them on these other days as well so they do go in for five days a week because having that, you just need a little bit of space so that you can be a good mum, wife and all those other things the rest of the time because it does use a lot of energy. My hormones definitely play a part in my ability, so I think that is

something that is really interesting. Being aware of your own cycles and hormonal habits that really do have an impact on how well I can cope with emotive situations, like you know being with a very breathless person or you know anything else along those lines? I think that's quite interesting to me as well, and I have to be mindful of that to think. OK, gosh, why am I crying all the way home? You know, then I think as a woman it is something that you do have to acknowledge as part of work as well, because it can be really difficult to manage those types of heightened emotions when you are already perhaps struggling anyway so I think it's checking in with yourself to think how that is.

I previously had monthly clinical supervision with a small group, the same facilitator who was a counsellor who was really lovely, and so we had that opportunity for one to one if we wanted it on an ad hoc or permanent basis so that was always very good. People have different views of clinical supervision and I think people should just be able to bring any sort of experiences that are affecting them if they want to share from work or home if that's something they feel 'cause it's all interlinked, isn't it? But there was a management opinion after a time that made it feel like it was going to become a tick box exercise because there would be an agenda and it was like any other meeting where you would have to meet the criteria to talk about the things you wanted to talk about so I didn't like that and our management was saying they wanted feedback on what was being discussed which our facilitator, the counsellor said I'm afraid I'm going to have to leave if it carries on with this this because this isn't the purpose or role of clinical supervision. This is not an MDT learning environment where we're appraising, or not appraising but reflecting on clinical situations. Although we might do that as part of that, we naturally, organically might If somebody had been struggling and said Oh well I just didn't know what to do with this particular person and we might say well, did you think about this or what would offer advice but there was nothing formal to it and I think it was a shame really because although it was clinical supervision. It was almost like, well, you're having an hour and a half of this time and we want to be able to measure it, but it's not really measurable. It shouldn't be something that you can put a metric against. Really, if they want to do anything like that, it really should just be a sort of a Wellness score of some sort, shouldn't there?

At the last place I worked everyone would just come in and breathe and just think, oh we can now all share, so I think it is really important to have a safe space for discussions, so I hope that's something that they will be offering at the organisation that I am at now, but we shall see. I think it is just everything is on hold because of COVID, particularly external people coming in. And I don't think it's something that's easy to have on teams, it's definitely nice to know it's coming.

Yeah, so It's hard, isn't it? We need more in our Tool kit so that we feel that we can equip people with the skills that they need as well. But then there's also the element of looking after yourself as well and making sure that you're having that time to reflect and support yourself as well. So, I do a lot of mindfulness and guided meditations that help me just close off from things that have happened and, you know, put those behind me and move on as well. I use the app CALM and it's really helped me.

I think that sometimes nurses do have more of a broad holistic approach than physios. Although they do deliver lots of intervention and skills there is just something different from the nursing approach. I think that we look into all aspects of life. Through the holistic assessment we take a caring, compassionate approach. I think that you either have a passion for respiratory or you don't. That's how I feel in a bit of an isolated role . It's important to surround yourself with other people that have that passion because that's what is missing in my work life as well. And then when you talk to other people that understand or respiratory conditions are their primary concern, they share the same passion. I think it really helps, supports and motivates you'.

Commentary on Fionas' crafted story

For Fiona, caring is a big part of her social and professional conscience, shaping how she sees herself in the world, *dasein*. While she visits her patients in a professional capacity, she brings herself personally to the role as a respiratory nurse specialist, and as a result describes the personal challenges resulting from professional encounters. This temporality, informed by the longevity of experience reveals her perspective has changed over time and she is now more aware of the personal impact of her professional role. Her attunement, shaped by her situatedness in the world is shown by her engagement, her understanding of being needed and valued by her patients and the responsibility she feels from this. This responsibility sits heavily with Fiona because she is so passionate about her work, she strives to do the best for her patients. She is aware of her thrownness into situations as a woman, a mother, a wife and a nurse and is conscious of these competing roles impacting her patient encounters. Her fallenness into her role is shaped by her own interpretation of being a CRNS, accepting her personal engagement as an important aspect of her role. She demonstrates *fursorge* in her desire to help her patients who are breathless with practical

tools. This could be a desire to leap in with interventions but her desire to provide emotional support and facilitate self-management usually results in her leaping ahead. This desire to help is not only fursogen, it is motivated by a discomfort in doing nothing because, in witnessing helplessness and her patient's Being-toward-death, she too is faced with this as a reality. This call to authenticity is painful for Fiona and something she cannot do if she is to be effective in her role supporting patients.

The distress of her patients suffering with breathlessness causes her to feel distressed and often overwhelmed. This might be because she has formed a relationship with a patient who has died and she feels their loss personally, sometimes she might feel a sense of personal responsibility when leaving a visit knowing the patient may not see anyone for a while, but often it is because there is no time in her day between patients to have the space to process her emotions. Fiona's engagement in her role comes at a cost to her personally when she gives so much of her emotional energy to patients and she works hard to redress this balance.

Reflections

Straight after the interview

This interview was with a community respiratory nurse who works from a hospice setting. Their remit was to have several specialist nurses for non-malignant disease so she was the only one of her kind within her team. We discussed managing the expectation raised by the medical model to treat conditions such as COPD and ILD when actually supporting people to live with their condition might be more enabling.

She and I got on very well as we seem to have a lot in common in terms of our passion and aspirations for our work. Her role was a new role so certain issues were still being ironed out but she was reflective and very honest about her own limitations and vulnerability coming to the job. It does strike me in these interviews how an individual's personality and passions are so pivotal in how they approach their job and for the patients it is more luck than

judgement. This considers the culture of the organisation and what is valued so that will reflect who is employed and the skills valued.

After crafting the story 11th Jan 2022

Fiona, more than most, talks about the burden of caring for her patients. She talks about it weighing heavily, low-grade grief and feeling overwhelmed yet she ends with sharing her passion for Respiratory Nurses and her love of the job. This apparent conflict of emotion is something that has been an emerging theme in the interviews so far and cannot be categorised in the binary sense of joy or burden but of more complex emotion in approaching the role of the community respiratory nurse. The apparent cost to the individual whilst acknowledged and explored is countered by the passion for caring for these patients. This idea of altruism needs to be unpicked. Is there something about the more you give the more you get? in opening up and being vulnerable do we somehow gain a deeper more intense yet meaningful patient encounter and experience? And that is what we inadvertently crave; knowing that we have witnessed something profound, intense and incredibly important? Making dichotomous distinctions about emotions is inadequate when we are dealing with a really complex interplay of emotions, needs and vulnerability from both nurse and patient. Being needed and being in a position of power and influence in a vulnerable situation gives identity and is an incredibly important role to take as Fiona shows.

Hillary Interview 8

Crafted story

'I've been in community respiratory care for about six years, all told. I absolutely fell in love with respiratory. I relocated for family reasons to {this area} in 2019 and have been there since, back doing what I really enjoy.

Certainly, in this area, I think we're the only service really and for anyone with respiratory problems that can help with breathlessness so that's a huge part of our role. All of our team have done modules in history taking and physical examination and most of us are prescribers so we've got those skills and we can take a really thorough history and look back and see what could be driving the breathlessness.

There is a chap that I saw last week, he is a long term patient of ours with very, very advanced COPD and very little functioning lung left really. He is on long term oxygen therapy and is very, very breathless all the time and even when he is just sitting still, is still quite breathless. He's on a reasonably high flow rate of oxygen as well, so sort of getting towards end stage really but, unfortunately, is relatively young and still has the mindset of wanting to be very active and wanting to go out and do things. He says things like "I sit here and think I can do X, Y and Z and then I get up and my body says actually no I can't do that".

And, and what particularly struck me when I saw him last week was that as we were drawing things to a close and I was getting ready to leave, he said, "do you know: I'd just like one day, where I can breathe. That's all I want, just one day". And I thought gosh, how dreadful to feel like every day is an absolute struggle for you.

[It makes me feel] a bit hopeless and helpless really; sorry. He's on maximal therapy and medically there's nowhere else that we can go, he is using things like fan therapy, breathlessness management techniques, he's done pulmonary rehab previously, done the breathlessness management course at the hospice previously.

And so you do just sort of feel like gosh; you're racking your brain almost. What else can I do? There must be something that I can do, I think as a nurse your whole ethos is about relief of suffering. You want to make people feel better and when you're faced with a situation where you can't make it better, that's really difficult and it's not a comfortable feeling to feel helpless and like there isn't anything I can do to make this situation better. When reflecting back [I think] am I doing enough? Is there something else that I should be doing? And that makes you feel quite critical of yourself when you're faced with a situation like that that is so challenging that you want to be able to do something even when there isn't necessarily something that you can do to make it better. I suppose it's that what spurs you on to keep going and to help your patients as much as you can and think, what I am doing is valuable and I want to do the best that I can. And also, then when you meet patients, when you get new referrals of people who are earlier in their disease process, doing everything that you can to try and stop it progressing to a point where they may be in that situation where every day is absolute struggle and and you know they can never escape from their breathlessness almost.

I think nursing is a naturally supportive and nurturing role so although we may not have an answer, or a treatment or a pill for want of a better term, I think that's a natural part of what a

nurse does; supporting somebody and I certainly find with my patients that even just sitting and listening to their concerns, not actually really saying an awful lot myself, you know, I'll often end the conversation and they say, you know I feel so much better now that i've spoken to you and I think well i've not really done anything other than listen to what you've got to say and understood your concerns and acknowledge that what you're going through is difficult and challenging. And, you know, I think that fits really well with nursing and I think that's almost a unique skill that nurses have to be able to do that and develop that therapeutic relationship with patients.

[Breathlessness] is difficult to witness and something that I think we as a team have found that other professionals who don't specialise in respiratory don't always have a good appreciation of, when you have medical colleagues writing things on discharge letters like they were just breathless, so they were sent home. It's such an aggravating thing to read because you think well no they're not just breathless, they live with that every second of every day they never get to escape from that, it's not just something small that can be written off, it should be taken seriously.

Fortunately, I have a very, very supportive team and there's lots of support in place. I think it's the most supportive environment I've ever worked in actually. We regularly have clinical supervision and discuss with each other so patients like that we try and make sure that everybody in the team sees them and so that a) that gets a fresh pair of eyes and other people might have different ideas and b) then it's not always the same person sort of carrying that burden of thinking goodness what am I going to do with this poor person. And so having a support network there is really important, and actually acknowledging that that has an effect on us as professionals is really important. And that said, there are always people at the end of the phone, and we do have very good relationships with all of the GPs locally as well and so we can always call and ask for advice if it's something that we're faced with that's not respiratory related and we don't know what to do and or how to address it.

[Support needs in the community] are definitely different [to the hospital] because you are on your own and isolated, a lot of the time when you're out on your visits and things. Whereas on the Ward you know that something can happen, but you can call on someone who's just over the way or just in another bay and they're there immediately, you don't have that same thing when you're in the Community on home visits. So often it's you having to deal with what's there at the time and then discuss it later or get advice later. From experience I've had in other areas, for example when I've worked in A&E when they've had a cardiac arrest

that's not been a successful resuscitation attempt the team that was working on that patient all went away for 10 minutes and had a debrief with the consultant and talked through everything. Which is obviously really supportive and really good but actually in our job that kind of mechanism doesn't exist. Where you're faced with a really challenging scenario and often you can't think about that or do anything with it at that point because you've got another two or three visits to go and do, you have to kind of park it for the rest of the day, while you do your other work.

[In the community] we have to seek out the support although not everybody naturally would seek it out. Some people will just carry that, and not do anything with it other than let it fester and stew and weigh down on themselves more heavily as time goes by. It is something that I think within our team we're quite good at picking up on for each other rather than being able to pick up on it ourselves, saying to one of your colleagues, are you alright? you seem like things are getting a bit on top of you. And so yeah, it's a real worthwhile thing to look at because it's something that I think even us as nurses ourselves we don't often stop and think actually Am I okay with this? Is this affecting me? With this kind of work people don't get better. We often look after them for a long time and build relationships with them over a period of time. And when you can see, somebody getting worse and worse and worse that you've known for a long time, that does, sometimes lay heavy on you'.

Commentary on Hilary's' crafted story

Hillary is non-binary preferring they/them pronouns.

Witnessing this man's predicament is personally and professionally challenging for Hillary both in being alongside his distress and in seemingly falling short of their expectation of what it means to be a nurse. Their expectation of themselves that as a nurse they will relieve suffering is confronted when, despite every practical intervention this man's breathlessness persists and his suffering is clearly not relieved.

For Hillary, this understanding of what it means to be a nurse comes from their subjective experiences shaping their cultural, social, historical and political perspective to arrive at this perspective. Their dasein is shaped by this and will shape their encounters with others. This desire to leap in to assist would meet Hillary's need to fulfil their role as they see it but there is nothing that can be done. This leaves exposure for Hillary to be-toward-death with their

patient and a feeling of helplessness and self-criticism. Such is this allocentric desire that rather than retreat, Hillary is spurred on to do their best for their patient. Hillary does recognise the skill of a nurse is to develop a therapeutic relationship with patients. However, while they recognise a connection is made with their patients by sitting and listening, acknowledging their concerns, they do not feel they have “done anything”, despite the patient saying they feel much better. In drawing alongside their patients, Hillary is actually leaping-ahead authentically releasing solicitude. Enabling their patients to stand on their own 2 feet and processing their thoughts and feelings, Hillary is reducing their dependency giving back care to themselves.

In advancing lung disease made known through breathlessness, the body is no longer ready-to-hand and functioning without issue. Breathlessness reveals the body is unready-to-hand, that there has been a breakdown or betrayal of the natural self. As an outward display of this breakdown, persisting refractory breathlessness demonstrates the body is unready-to-hand to Hillary and without relieving this, suffering will never be relieved, and they will therefore not feel they have fulfilled their role as a nurse. Hillary is explicit about their understanding of the role of the nurse in the relief of suffering and how there is a dissonance in achieving this in a speciality where generally people don't get better, suffering persists, and therapeutic relationships are forged over long periods of time. Yet rather than look to remove themselves from this respiratory nurse role, Hillary speaks of how they love the role, the passion and advocacy for their patients. This complexity of joy and sorrow in the role of the nurse needs further exploration.

Reflections

18th May 2021

This was a good interview, but I didn't feel I achieved a good rapport with the nurse. It was my first non-binary nurse and while they answered my questions honestly and with

thoughtfulness, I felt they thought there was a right answer and the conversation didn't flow as naturally as it has done with other participants. There was empathy with patients and an appreciation and understanding of the autonomy of the role and the challenge of the supporting people with breathlessness. Interestingly their team does not have any physios at all it is entirely nurse lead. The PR service has been commissioned by BOC.

After crafting the story 18th Feb 2022

I remember this interview to be uncomfortable and my thoughts were I did not engage with the participant but in watching and re-reading it I can see someone who is very generous and compassionate in their offering. I think my discomfort came from the non-binary and getting terminology right and not wanting to say the wrong thing. But actually, this nurse gave an incredibly honest and thoughtful account and a lot for me to consider. As I look at these interviews, I can see my HP interviewing techniques are weak and do not take full advantage of the cues the participants give so I do not explore their experiences in the depth as I could've done.

That said, by interview 8 I am starting to see some saturation and recurrent themes from other interviews around "weighing heavy", not having space to process difficult experiences, feeling helpless and hopeless in the face of refractory breathlessness. I also can see the emerging complexity of the role of the nurse faced with adversity and challenge yet getting great satisfaction and showing dedication to a speciality that is really challenging. This needs a lot of in-depth exploration and analysis.